# CARING FOR THE DEMENTIA RESIDENT

## ENSURING REGULATORY-COMPLIANT CARE

Frosini Rubertino, RN, BSN, C-NE, CDONA/LTC

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HCPro
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# About the Author

Frosini Rubertino, RN, BSN, C-NE, CDONA/LTC, is a regulatory specialist with more than 25 years of experience in the healthcare industry. She is the author of HCPro's *The QIS Mock Survey Guide*, *The Medicare Billing Manual for Long-Term Care*, *The Complete Guide to Long-Term Care Medicare Billing*, *QAPI: A Nursing Home's Guide to Implementation and Management*, *Dementia Care: A Handbook for Long-Term Care*, and TrainingInMotion.org's *Carmelina: Essential Nursing Systems for Long-Term Care.*

As the founder of TrainingInMotion.org and instructor for HCPro's Boot Camps, she is a nationally recognized trainer and speaker, advising long-term care organizations in regulatory compliance and how to maintain excellence in their respective roles.

Rubertino has contributed to several HCPro products, including *PPS Alert* and *Billing Alert for Long-Term Care*, and has authored several articles for publications such as *Provider Magazine* and *The Eden Alternative*. She is often a featured speaker on clinical systems, culture change, performance improvement, and Medicare for state and private organizations across the country.

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# Foreword

*Dementia.* It can happen to anyone. It has no allegiance to any one culture, gender, or geographic location. The World Health Organization (WHO) reports there are an estimated 35.6 million people living with dementia worldwide. The number is expected to double by 2030 and is likely to triple by 2050. The Alzheimer's Association reports Alzheimer's-type dementia as the 6th leading cause of death in the United States. Approximately 200,000 individuals who are younger than 65 years of age are stricken with the disease. Demographics are shifting. Inevitably, many of us who are now healthcare professionals and caregivers may be diagnosed with dementia. The care we receive will be influenced by the progress we make today in dementia care.

## WHO Dementia Facts

1. Dementia is not a normal part of aging
2. About 35.6 million people live with dementia worldwide
3. A new case of dementia is diagnosed every 4 seconds around the world
4. The economic global impact of dementia care is $604 billion
5. Dementia caregivers experience a high level of stress
6. Early diagnosis can improve quality of life
7. Many people with dementia are discriminated against through the use of physical and chemical restraints
8. More awareness and advocacy for dementia care are needed to improve quality of life

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9. More research is required to develop new and more effective interventions and treatments
10. Dementia is a public health priority, needing education to improve attitudes and understanding of the disease

We are a world in transition, beginning to recognize that dementia care is an interdisciplinary collaborative approach that must result in a collective impact. Key elements of dementia care include:

- Staff education
- Environmental adaptations
- Provisions for recognizing and meeting spiritual and psychological needs
- Implementation of a social model of care that allows the resident to perform valued activities and participate in their own care to the full extent of their capabilities
- Avoiding unnecessary antipsychotic use
- Providing support for family and caregivers

The interdisciplinary collaborative approach includes not only each department in the facility but also the continuum of care, provider to provider. As the disease progresses, so should our approaches to accommodate ongoing quality of life. It's a journey of caring enough to do the right thing and caring enough to do more.

The vision of the future of dementia care is built on the foundation of person- and family-centered care that encompasses a collaborative approach for caregiver engagement and support. When providers, survey agencies, and advocacy groups form a strong alliance, there is great power to make a positive impact to improve care practices, even beyond dementia care. Person-centered living is possible as we continue to discover and appreciate the possibilities in the treasure of a life worth living in America's nursing homes.

National and regional initiatives and alliances continue to multiply. However, at the facility level, much more needs to be accomplished in areas such as decision-making, caregiver


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stress, education, attitudes, and awareness if these initiatives and alliances are to flourish. From reducing unnecessary antipsychotic use to modifying our behavior management approaches and optimizing interaction with our residents, our journey has only just begun, as dementia care continues to be at the forefront of long-term care initiatives. At a more global level, creating incentives for quality dementia care, streamlining care processes, handling workforce shortages, and dealing with staffing costs will continue to be challenges.

Use all the resources you can find, collaborate with other professionals, nurture resident and family relationships, set expectations, and lead by example. It is simply the right thing to do.

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# Chapter 1: Understanding Dementia

Understanding dementia encompasses facing the challenges with our current state of dementia care. There is stigma attached to the label of dementia, as well as a lack of adequate education on dementia care and abuse prevention—both for staff and family members. Operational challenges exist due to a lack of dementia care training, and there are financial challenges for people who have family members with dementia.

## Stigmatization

Our traditional dementia care practices were shaped by stigma, describing dementia patients with phrases such as "She isn't in her right mind," He suffers from dementia," "He's checked out," "Crazy," "Out of it." Dementia care has become a societal challenge to change how we view people living with dementia. We often fail to see the real person who lies within, and we must recognize that those diagnosed with dementia are not at the end of their life. They may continue to live for many more years with an internal vitality that goes unrecognized due this stigma, resulting in an environment that is more focused on controlling behaviors and not acknowledging patients' worth instead of an environment that fosters meaningful living that is built around the people's strengths and preferences.

## Education and Support

Within our long-term care facilities, a vast majority of our residents live with the diagnosis of dementia. However, while we strive to improve our care practices, a more collaborative effort is needed to provide adequate education on dementia care and abuse

prevention for our staff, as well as education and support for family members who struggle to understand and accept the prognosis of dementia. Education and support are an investment of time and money; otherwise, the ultimate cost may manifest into poor care outcomes, decreased quality of life, and strained relationships with our residents' family members.

## Operational

Operational challenges exist with a lack of dementia care training to address the progressive memory impairments, declining decision-making skills, shorter attention spans, and unmet needs that result in challenging behaviors. For example, many providers utilize antianxiety medication as the intervention when a resident is combative during personal care instead of first trying to determine what it is about the task that seems to be emotionally distressing to the resident. Since people with dementia connect more on an emotional level than a cognitive level, operational strategies should be focused on building more meaningful relationships that can influence the care episode. Operationally, we tend to staff our facilities according to state requirements instead of the amount of time needed to address each resident's emotional and physical needs, which contributes to staff being unable to meet the resident's cognitive needs. Until our current reimbursement structures are redesigned, our operational options may be limited.

## Financial Stressors

The Alzheimer's Association has estimated that Medicaid spends 19 times more for Medicare beneficiaries with a dementia diagnosis than for those with a nondementia diagnosis. People who have family members with dementia may struggle financially to keep their loved ones at home for as long as possible to avoid the more staggering costs of long-term care placement.

Clearly, destigmatizing the global perspective of dementia and changing the standard for our current dementia care systems will guide us into a realm where the human spirit is as precious in our elders with dementia as it is in our young children.

## Initiatives for Quality Dementia Care

Dementia care within long-term care continues to evolve, bringing with it new and higher expectations to improve quality of life and quality of care. However, a gold standard has yet to be established, so we are left with assembling information from a variety of resources to provide quality dementia care. If we are resourceful and open-minded, we can begin to develop our facility's own gold standard for dementia care that includes meeting needs beyond the activities of daily living into a more holistic, person-centered framework of services that maintains the focus on

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person-centered living. There have been several recent significant strides and events toward the goal of improving how we manage our dementia care practices and redefine our dementia care programs.

The American Medical Directors Association (AMDA), dedicated to long-term care medicine, published clinical practice guidelines for dementia care in nursing homes. AMDA works closely with Congressional House and Senate leaders to address the use of antipsychotics in nursing homes, and its vice president has testified at the Senate Special Committee on Aging hearing entitled "Overprescribed: The Human and Taxpayers' Costs of Antipsychotics in Nursing Homes." The hearing testimony of Daniel R. Levinson, Inspector General of the Department of Health and Human Services, was published November 30, 2011. The hearing examined the use of antipsychotics for nursing home residents with dementia despite the Food and Drug Administration's black box warnings for use and revealed that one in five drug claims for atypical antipsychotics either were prescribed in a dosage that was too high or were prescribed for too long. Nearly half of the claims were not within medically accepted indications for use, and there was evidence that some drug manufacturers have illegally marketed these medications for off-label use. The study concluded that it is imperative to address the overuse and misuse of antipsychotic medication among nursing home residents, and the Office of Inspector General (OIG) will continue to conduct reviews to determine whether nursing homes are administering thorough enough assessments for antipsychotic use.

A June 2014 report titled *Improving Dementia Long-Term Care*, from the RAND Corporation, the nation's largest independent health policy research institution, offers a policy blueprint under five umbrella objectives to engage local, state, and national stakeholders that influence policy decision around dementia. These objectives include:

1. Increase public awareness of dementia to quell its pervasive stigma and facilitate earlier detection of its symptoms
2. Improve access to and use of long-term services and supports
3. Promote high-quality, person- and caregiver-centered care
4. Provide better support for family caregivers of people with dementia
5. Reduce the burden of dementia long-term services and supports

The blueprint addresses policy and procedures related to researching, preventing, diagnosing, and treating dementia. This report has ignited improvements to the care delivery system in both the community and the clinical care environment that will affect future policy-making decisions on existing regulations. These decisions may include expansion of home- and community-based services, linking together long-term care insurance and health insurance, improving outreach to the public on dementia diagnosis and care, and wider use of cognitive assessment tools by providers.

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The Dementia Action Alliance, a people's movement, devotes itself to dementia care and is not limited to cure or treatment. The Eden Alternative, Planetree, and the AMDA Society for Postacute and Long-Term Care serve as its leadership team. They lead a national initiative to facilitate the collective energies and voices to implement change. Their movement is strong as they continue to work toward improving dementia care globally through collective impact.

The OIG released a report in August 2014 titled *Nursing Facilities' Compliance with Federal Regulations for Reporting Allegations of Abuse or Neglect*. Federal regulations require nursing facilities to develop and implement policies regarding reporting allegations of abuse, neglect, mistreatment, injuries of unknown origin, and misappropriation of resident property. Any allegations of abuse or neglect must be reported to the facility administrator or designee and the state survey agency within 24 hours, and the results of the allegations must be reported to the same authorities within 5 working days.

The OIG studied sampled policies, examined allegations of abuse or neglect, and surveyed administrators for those sampled facilities. The result of the study revealed 85% of nursing facilities reported at least one allegation of abuse or neglect, and only 76% maintained policies that address federal regulations for reporting allegations. Further, only 61% had documentation that supported the facility's compliance with the regulation. Lastly, only 53% of abuse or neglect allegations were reported.

From an additional regulatory perspective, in March 2010, Congress passed the Patient Protection and Affordable Care Act (PPACA), often referred to as the Affordable Care Act (ACA), with Part III, Section 6121, amending the Social Security Act's, Sections 1829 and 1919 requirements to include initial and ongoing dementia management training and abuse prevention training for nursing assistants in section A9(i), which states:

> *Requirements for the approval of nurse aide training and competency evaluation programs, including requirements relating to (I) the areas to be covered in such a program (including at least basic nursing skills, personal care skills, recognition of mental health and social service needs, care of cognitively impaired residents, basic restorative services, and residents' rights) and content of the curriculum (including, in the case of initial training and, if the Secretary determines appropriate, in the case of ongoing training, dementia management training, and patient abuse prevention training, (II) minimum hours of initial and ongoing training and retraining (including not less than 75 hours in the case of initial training), (III) qualifications of instructors, and (IV) procedures for determination of competency.*

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In 2011, the OIG released a report, *Medicare Atypical Antipsychotic Drug Claims for Elderly Nursing Home Residents*, which indicated 83% of nursing home residents did not have a proper diagnosis to justify the use of their antipsychotic medications, which were being utilized for off-label purposes. AMDA now includes a free interactive course to its members aimed at decreasing inappropriate antipsychotic use in persons with dementia.

In 2012, the Centers for Medicare & Medicaid Services (CMS) launched the National Partnership to Improve Dementia Care, now referred to as Partnership to Improve Dementia Care in Nursing Homes. An important aspect of this initiative is to reduce the unnecessary use of antipsychotics. Issues such as pain management, caregiver stress, and decision-making on dementia care interventions also remain areas of concern. A pilot project is under way to examine the process of dementia care in nursing homes and to take a closer look at the prescribing of antipsychotics. Among other providers, advocacy groups, and caregivers, AMDA also joined this partnership.

From a survey perspective, agencies are working to enhance survey accuracy in the area of dementia care in order to evaluate and document care practices. The CMS Center for Clinical Standard and Quality/Survey and Certification Group released a memorandum in May 2013 (S&C: 13-35-NH), conveying clarifications for the survey process regarding dementia care and unnecessary drug use. Another memorandum was released in April 2014 (S&C: 14-22-NH) regarding a focused survey process to assess dementia care, and it outlines some fundamental principles. These include:

1. **Person-centered care.** CMS requires nursing homes to provide a supportive environment that promotes comfort and recognizes individual needs and preferences.

2. **Quality and quantity of staff.** The nursing home must provide staff, both in terms of quantity (direct care as well as supervisory staff) and quality to meet the needs of the residents as determined by resident assessments and individual plans of care.

3. **Thorough evaluation of new or worsening behaviors.** Residents who exhibit new or worsening behavioral or psychological symptoms of dementia (BPSD,) should be evaluated by the interdisciplinary team, including the physician, in order to identify and address treatable medical, physical, emotional, psychiatric, psychological, functional, social, and environmental factors that may be contributing to behaviors.

4. **Individualized approaches to care.** Current guidelines from the United States, United Kingdom, Canada, and other countries recommend use of individualized approaches as a first-line intervention (except in documented emergency situations or if clinically contraindicated) for BPSD. Utilize a consistent process that focuses on a resident's individual needs and tries to understand behavior as a form of communication to reduce behavioral expressions of distress.

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5. **Critical thinking related to antipsychotic drug use.** In certain cases, residents may benefit from the use of medications. The resident should only be given medication if clinically indicated and as necessary to treat a specific condition and target symptoms as diagnosed and documented in the record. Residents who use antipsychotic drugs must receive gradual dose reductions and behavioral interventions, unless clinically contraindicated, in an effort discontinue these drugs.

6. **Interviews with prescribers.** The prescribers must validate the reason for using a psychopharmacological agent or any other interventions. The survey team will conduct interviews with the physician, other primary provider (nurse practitioner, physician assistant), behavioral health specialist, pharmacist, and other team members to evaluate the process of care.

7. **Engagement of resident and/or representative in decision-making.** Residents and/or their family or representative must be involved in the discussion of potential approaches to address the behavioral symptoms. These discussions should be documented in the medical record.

Survey agencies will use, at a minimum, regulation F309 (Quality of Life) and F329 (Unnecessary Medications) to investigate services for a resident with dementia. During the traditional survey process, surveyors will ask for "a list of names of residents who have a diagnosis of dementia and who are receiving, have received, or presently have PRN orders for antipsychotic medications over the past 30 days." The administrator or director of nursing will be asked to "describe how the facility provides individualized care and services for residents with dementia and to provide policies related to the use of antipsychotic medication in residents with dementia." In the Quality Indicator Survey process, surveyors will not necessarily ask for information regarding regarding antipsychotic use in those with dementia since their survey software will automatically identify the required survey sample. A document titled "Resident with Dementia Checklist" is available to guide the investigation for both survey processes that includes assessment and underlying cause identification, care planning, implementation of the care plan, care plan revision, monitoring, follow-up, and quality assessment and assurance.

### *F309 Quality of care*

**Regulatory language:**

Each resident must receive and the facility must provide the necessary care and services to attain or maintain the resident's highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.

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### The intent of F309

The facility must ensure that the resident obtains optimal improvement or does not deteriorate within the limits of a resident's right to refuse treatment and within the limits of recognized pathology and the normal aging process.

## *F329 Unnecessary drugs*

**Regulatory language:**

1. **General.** Each resident's drug regimen must be free from unnecessary drugs. An unnecessary drug is any drug used:

   (i) In excessive dose (including duplicate therapy)

   (ii) For excessive duration

   (iii) Without adequate monitoring

   (iv) Without adequate indications for its use

   (v) In the presence of adverse consequences that indicate the dose should be reduced or discontinued

   (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

   (ii) Residents who use antipsychotic drugs receive gradual dose reductions and behavioral interventions, unless clinically contraindicated, in an effort to discontinue these drugs

### The intent of F329:

The intent of this requirement is that each resident's entire drug/medication regimen be managed and monitored to achieve the following goals:

- The medication regimen helps promote or maintain the resident's highest practicable mental, physical, and psychosocial well-being, as identified by the resident and/or representative(s) in collaboration with the attending physician and facility staff
- Each resident receives only those medications, in doses and for the duration clinically indicated to treat the resident's assessed condition(s)

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- Nonpharmacological interventions (e.g., behavioral interventions) are considered and used when indicated, instead of, or in addition to, medication
- Clinically significant adverse consequences are minimized
- The potential contribution of the medication regimen to an unanticipated decline or newly emerging or worsening symptom is recognized and evaluated, and the regimen is modified when appropriate

Together, the PPACA, the CMS National Partnership, revised surveyor guidance, dementia care studies, advocacy groups, and care alliances will significantly expand the scope of quality dementia care expectations in nursing homes across America, focusing on staff education and accountability for person-centered approaches to meet the care needs of those with dementia. The mutual goals of these initiatives foster and accelerate our efforts in dementia care practices, jump-start our efforts to address the urgent challenge to improve processes, engage stakeholders, and provide a blueprint to meet the moral, ethical, and legal issues of dementia care in our country.

## Dementia and Person-Centered Care

To understand the impact of person-centered care, we must first understand the pathophysiology of dementia. The term *dementia* is used to describe a group of disorders that affect daily functioning. It is not a specific disease but is considered an umbrella term for the group of disorders with symptoms that affect physical, social, and cognitive function. Although there are several types of dementia, Alzheimer's disease is the most common progressive irreversible dementia. Other irreversible dementias include vascular dementia, mixed dementia, Parkinson's disease, and Lewy body. Less common are frontotemporal, Huntington's, Wernicke-Korsakoff syndrome, Creutzfeldt-Jakob disease, and AIDS-related dementia.

The following table depicts the similarities and the differences between each type of dementia.

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## Table 1.1 Types of Dementia

| | |
|---|---|
| **Alzheimer's Disease Dementia (DAT–Dementia, Alzheimer's Type)** | The most common type of dementia.<br>Accounts for 60%–80% of all dementias.<br>Brain cells degenerate and die, causing memory and mental function declines. |
| **Vascular** | Caused by impaired blood flow to the brain, such as after a stroke from a blood clot or hemorrhage.<br>May also be a result of other conditions, including the brain being deprived of oxygen due to vascular disease, head injuries, or heart attack.<br>High cholesterol, smoking, and high blood pressure significantly increase the chances of vascular dementia. |
| **Mixed** | Having symptoms of more than one type of dementia. For example, a combination of Alzheimer's dementia and vascular dementia. |
| **Lewy Body** | May result in muscle rigidity, slow movement, tremors, and hallucinations.<br>May also go back and forth from moments of clarity to moments of confusion.<br>Often misdiagnosed as Parkinson's disease due to the appearance of tremors, or Alzheimer's disease due to the memory loss. |
| **Parkinson's** | Approximately 50% of those with Parkinson's disease may experience dementia.<br>May begin with tremors, but progress to speech problems such as mumbling.<br>Often appears to have no facial expression.<br>Arms may not swing when walking. |
| **Frontotemporal** | Affects frontal and temporal lobes of the brain.<br>Symptoms will affect personality, behavior, and language. |
| **Huntington's** | Will include behavior changes and abnormal movements of the face and extremities.<br>May experience difficulty swallowing and speech impairment. |
| **Wernicke-Korsakoff** | This is a degenerative brain disorder.<br>Caused by lack of vitamin B1, alcohol abuse, prolonged vomiting, or side effects of chemotherapy. |
| **Creutzfeldt-Jakob** | Rare, degenerative, and fatal.<br>Progresses quickly leading to death. |
| **AIDS-related** | Inability to concentrate, with poor short-term memory.<br>May include motor dysfunction and behavioral changes. |

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### *The effects of dementia on daily life*

Dementia is not a normal part of aging and is most common after the age of 65. More and more, we are seeing early onset in individuals who are 30–50 years old. The following areas may be compromised at different levels for each resident depending on the progression of his or her specific type of dementia.

## Table 1.2 Compromised Areas of Dementia

| | |
|---|---|
| **Memory** | Unable to remember recent or long-term events. |
| **Concentration** | Unable to stay focused on the task. |
| **Orientation** | Does not know who he or she is, what he or she is doing, what time or day it is, where he or she is. |
| **Language** | Experiences difficulty communicating or making his or her needs known, understanding what others are saying. |
| **Visuospatial** | Cannot make sense of surroundings and objects, may not be able to find own room, running into furniture. |
| **Judgment** | Makes poor safety decisions. |
| **Sequencing** | Unable to do things in a logical order. |
| **Patience** | Cannot remain calm in an environment that is confusing to him or her. |
| **Physical function** | At risk of injury and nutritional deficiency due to memory loss, impaired mobility, unidentified pain, and self-care deficits. |
| **Social** | Experiences impaired relationships with family and caregivers. |
| **Emotional** | May experience outbursts, crying, depression, apathy, yelling, or anxiety. |
| **Other** | Wanders unsafely; unable to make healthcare decisions or financial decisions. |

### *How does dementia influence person-centered care?*

Each symptom intervention must be targeted to the individual needs of each resident. Not all residents with dementia have the same needs. Personalities, culture, social history, physical limitations, type of dementia, level of education, and severity of dementia symptoms are all factors requiring consideration for an effective dementia care program and will influence how an individual reacts in a variety of life situations.

Resultant behaviors in an individual with dementia may be a product of frustration, loneliness, boredom, fear, helplessness, or confusion. Thus, the focus of dementia care needs to be person-centered and holistic. The following examples show person-centered care approach case studies.

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| **Name/Age:** Mrs. Kramer/84 years old | |
|---|---|
| **Diagnosis:** Alzheimer's dementia, high blood pressure, and diabetes | |
| **Prior history** | She enjoyed vegetable gardening and caring for her rose bushes. |
| **Trigger** | No opportunity to go outside since admitted to nursing home. |
| **Resultant behavior** | Agitation during idle time spent between to indoor activities in facility. |
| **Person-centered care approach** | Provide resident the ability to go outside, participate in gardening, if available, or an area in the facility to accommodate a small indoor garden. |

| **Name/Age:** Mr. Smith/76 years old | |
|---|---|
| **Diagnosis:** Mixed dementia | |
| **Prior history** | Loves to read. |
| **Trigger** | Doesn't have books in room. Facility does not have a library. |
| **Resultant behavior** | Frustrated by lack of ability to read. |
| **Person-centered care approach** | Read to resident one–on–one when staff sees he is beginning to become frustrated, focusing on topics of interest. |

| **Name/Age:** Mrs. Benedict/69 years old | |
|---|---|
| **Diagnosis:** Alzheimer's dementia, early stages | |
| **Prior history** | Owned a catering business, enjoyed baking. |
| **Trigger** | Most activities provided are too confusing to follow, so she's avoiding them. |
| **Resultant behavior** | Confusion and helplessness at not being able to follow/remember steps to provided activities of interest. |
| **Person-centered care approach** | Include her in a baking activity, reminding her each step of the way of the ingredients and directions on preparation. If the topic is too complicated, use pre-mixed products such as cookie dough rolls that can be easily prepared. |

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| **Name/Age:** Mr. Silverton/80 years old | |
|---|---|
| **Diagnosis:** Alzheimer's dementia | |
| **Prior history** | Career construction foreman, traveled between sites overseeing workers. |
| **Trigger** | Needs to keep busy. Does not like boredom. |
| **Resultant behavior** | Wanders in and out of rooms, frequently attempts to leave facility. |
| **Person-centered care approach** | His behaviors may best be managed by determining what times he begins to wander and including him in a small–group activity with adequate supervision. Consider providing safe tools (tape measures, clipboard, blueprints) that are reminiscent of his work day. |

| **Name/Age:** Mrs. Perry/74 years old | |
|---|---|
| **Diagnosis:** Lewy body dementia | |
| **Prior history** | Does not speak fluent English. Lived with her daughter who interpreted conversations for her. |
| **Trigger** | Wants to understand what people are saying. |
| **Resultant behavior** | She becomes frustrated during dressing, resulting in combative behavior when staff attempts to complete the entire dressing task for her. |
| **Person-centered care approach** | Her behaviors may best be managed by allowing her to participate in her care, breaking down the task of dressing into smaller tasks, and giving her time to complete each step. Use cue cards for staff with simple words and phrases in her preferred language. |

| **Name/Age:** Mr. Cunningham/82 years old | |
|---|---|
| **Diagnosis:** Mixed dementia | |
| **Prior history** | Retired accountant. |
| **Trigger** | Has osteoarthritis and rheumatoid arthritis. Requires frequent administration of PRN pain medication throughout the day. Gets frustrated when he attempts to write due to pain in his fingers. |
| **Resultant behavior** | He becomes agitated when staff approaches him for transferring and positioning. Has stopped participating in activities. |
| **Person-centered care approach** | Managing his pain symptoms with a program that anticipates the pain, rather than responding to it when he already hurts, may help improve his response to caregiving. Consider accounting supplies for 1-on-1 activity sessions. |

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| **Name/Age:** Mrs. Lentz/78 years old | |
|---|---|
| **Diagnosis:** Vascular dementia | |
| **Prior history** | Was previously able to be independent with her healthcare decisions. Minimal chronic conditions. |
| **Trigger** | Documentation in the medical record indicates she has not had her ears examined for over three years. She is having difficulty hearing. |
| **Resultant behavior** | Becomes frustrated and eventually agitated when staff attempts to verbally interact with her. |
| **Person-centered care approach** | A simple earwax removal procedure by the physician may unblock her ears and help her hear what staff is saying to her, resulting in fewer episodes of frustration and agitation. Teach staff to speak slowly face-to-face and allow time for her to process and respond. |

| **Name/Age:** Mr. Carlton/81 years old | |
|---|---|
| **Diagnosis:** Parkinson's dementia, and benign prostatic hypertrophy (BPH), and congestive heart failure. | |
| **Prior history** | Urinary urgency from BPH. Bathroom door was within 6 feet of bed at home. Takes a diuretic at 7 a.m. each morning. |
| **Trigger** | He wanders in and out of rooms after breakfast each day. |
| **Resultant behavior** | When he is found in other resident rooms, he is often incontinent. He is most likely attempting to find a bathroom. |
| **Person-centered care approach** | Anticipating his toileting needs, after a toileting diary is completed and a prompted toileting plan created may decrease the wandering because his need was met. |

| **Name/Age:** Mrs. Lampin/83 years old | |
|---|---|
| **Diagnosis:** Parkinson's dementia. | |
| **Prior history** | Former night-shift nurse supervisor. |
| **Trigger** | Accustomed to napping after breakfast and after lunch. However, she is often left up in her wheelchair at those times. |
| **Resultant behavior** | She becomes uncooperative and agitated with staff during those times of the day. Has difficulty falling asleep at night. |
| **Person-centered care approach** | Accommodating her naps may eliminate those behaviors, or accommodate her when she chooses to stay awake at night. Provide night time activities when awake with safe nursing supplies (mock medical record, stethoscope, etc.) |

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In many cases, behavior may be a response to caregiver behaviors and actions. Consider how a resident may respond to the following situations:

- Scheduling showers for a resident who previously took only baths
- Beginning a task without first informing the resident what you are going to do
- Physically blocking a resident who is wandering
- Using the word *no* to stop a resident from doing something
- Waking residents up early in the morning when they may prefer to sleep in later
- Taking a resident into a place with high noise levels and bright lights
- Not interacting with the resident during care delivery, talking to others while delivering care
- Moving too quickly through the task, hurrying the resident
- Passing the resident in the hallway, day after day, month after month, without acknowledgment
- Responding to call lights with "What do you want?" or "What do you need?"

## Staffing to Meet Dementia Needs

Person-centered care requires the education of staff, residents, and families, with substantial coordination between interdisciplinary team members, to create alternative modalities to possible and potential triggers of behaviors.

In addition to education, implementing person-centered care approaches may require staffing levels that are beyond your state requirements. Other than the federal requirement that there must be a registered nurse on duty 8 hours per day, each state has minimum staffing requirements based on resident-to-staff ratios, total census, or some other methodology. However, this does not exclude the facility from providing sufficient staffing to meet the needs of the residents, especially those with dementia. In fact, F-tag F353: Nursing Services addresses sufficient staffing with the intent to ensure sufficient qualified nursing staff is available on a daily basis to meet the care needs of each resident in an environment that will enhance quality of life. This regulatory F-tag 353 specifically states:

> *The facility must have sufficient nursing staff to provide nursing and related services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident, as determined by resident assessments and individual plans of care.*

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With the expanding scope of healthcare improvement initiatives, our industry may prompt future changes in the federal regulatory staffing requirement for long-term care. This could lead to an expectation to have a direct care RN on duty 24 hours per day, 7 days per week. Higher RN-to-resident ratios can lower antipsychotic use, decrease the number of acquired pressure ulcers, decrease restraint use, decrease cognitive decline, and result in fewer urinary tract infections, less weight loss, less decline in function, and a reduced number of avoidable rehospitalizations. RNs would be available to continually monitor and assess, reevaluate interventions, and facilitate and lead a team of caregivers. In a more complex, more subacute long-term care environment, the high level of skill, knowledge, and oversight can improve outcomes for all residents, not just those with dementia.

Although staffing to meet care needs and skills is necessary, the foundation for success is to promote a culture where staff members engage with each other in the coordination of care delivery. What we communicate is just as important as how we communicate. Common communication problems are blaming others, reluctance to interact with other department members, and deferring responsibilities. These staff behaviors can directly affect resident behaviors. Building a work culture where the rule of engagement is to practice mutual respect for each other can be contagious if it is consistently an expectation.

## Care Planning for Dementia Needs

Too often, the plans of care focus on physical functioning needs and are prepared solely by the Minimum Data Set (MDS) coordinator. We can improve this practice by collaboratively reviewing the results of the activity assessment, dietary assessment, social service assessment, history and physical, and resident interviews, as well as input from family or significant others. Many facilities choose to develop a separate care plan for nursing assistants in addition to the one generated by the MDS coordinator. Either way, generic care plans should be developed collaboratively with a holistic approach for safe, meaningful living. Care plans are no longer pulled from a drawer. Each intervention must be based upon the root cause of the problem with consideration given to the physical and biographical data of each resident.

From education to staffing to care planning, it will take time to develop a culture of person-centered care approaches for your facility. It is best to begin with the individuals with the most challenging behaviors or distress. You will want to assemble and educate a dementia care team that will work collaboratively with other disciplines and the family to identify the root cause of the behavior and implement interventions that target those causes. Keep in mind that all behavior is purposeful. Find out what the resident is trying to do and why he or she is trying to do it, and then figure out how to meet that need.

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# CARING FOR THE DEMENTIA RESIDENT:
## ENSURING REGULATORY-COMPLIANT CARE

Providing quality care and aid to the vast majority of nursing home residents diagnosed with dementia can be challenging; it requires extraordinary care and special training to work with these individuals and their families. In an effort to ensure quality care for residents with dementia, CMS launched a campaign that calls on long-term care facilities to evaluate their existing dementia care approaches and work toward improving the quality of life and restoring good health by accurately treating and assessing pain, increasing resident and family satisfaction, decreasing staff turnover, reducing restraints, and minimizing the use of antipsychotic medications for the treatment of dementia-related behaviors.

With the help of ***Caring for the Dementia Resident: Ensuring Regulatory-Compliant Care,*** long-term care facilities can accomplish the goals of CMS' initiative by delivering person-centered, comprehensive, and interdisciplinary care to residents with dementia and protecting those residents from being prescribed antipsychotic medications unless there is a valid, clinical indication and systematic evaluation process established.

This useful resource will enable long-term care providers to:

- Build unique dementia care programs that will address the various needs and concerns of residents diagnosed with dementia
- Develop training that will meet the educational needs and requirements of staff members working in dementia care units and other units housing residents with Alzheimer's disease
- Help nursing staff understand the unique, challenging care needs of residents with Alzheimer's and dementia at each stage of the disease's progression
- Use person-centered care approaches to reconnect and build better relationships with residents and their families
- Educate staff on how to perform hands-on techniques to engage residents with dementia, implement suitable strategies to appropriately manage dementia-related behaviors, and provide assistance and assurance to residents' family members
- Achieve compliance with the eight goals of CMS' dementia care initiative

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