

DEMENTIA CARE

A Handbook
for Long-Term Care

Social Services Staff

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

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a division of BLR

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About the Author

Frosini Rubertino, RN, BSN, is a regulatory specialist with over 25 years of experience in the healthcare industry. She is the author of *The QIS Mock Survey Guide* (HCPro); *The Medicare Billing Manual for Long-Term Care* (HCPro); and *Carmelina: Essential Nursing Systems for Long-Term Care* (TrainingInMotion.org).

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

She is also a contributor to numerous publications including *PPS Alert for Long-Term Care*, *Billing Alert for Long-Term Care*, and the author of several published articles in *Provider Magazine* and *The Eden Alternative*®. She is often a featured speaker regarding clinical systems, culture change, performance improvement, and Medicare for state and private organizations across the country.



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 is an estimated 35.6 million people living with dementia worldwide. That 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 sixth-leading cause of death in the United States. Approximately 200,000 individuals who are younger than 65 years old are stricken with the disease.

WHO dementia facts

1. Dementia is not a normal part of aging
2. 35.6 million people live with dementia worldwide
3. A new case of dementia is diagnosed every four seconds around the world
4. The economic impact of caring for people with dementia in the United States is \$604 billion
5. Dementia caregivers experience a high level of stress

6. Early diagnosis can improve the quality of life for people with dementia
7. Many people with dementia are discriminated against through the use of physical and chemical restraints
8. More awareness and advocacy for dementia care is needed to improve the quality of life for people with dementia
9. More research is needed to develop new and more effective interventions and treatments
10. Dementia is a public health priority, in which the public needs more education about it to improve attitudes and understanding of the disease

Dementia care is an interdisciplinary collaborative approach. Key elements of dementia care include staff education, environmental adaptations, provisions for recognizing and meeting spiritual and psychological needs, the implementation of a social model of care that allows the resident to perform valued activities and to participate in their own care to the full extent of their capabilities, avoiding unnecessary antipsychotic use, and providing support for family and caregivers. The interdisciplinary collaborative approach includes not only each department in the long-term care facility, but across the continuum of care, provider to provider. As the disease progresses, so should our approach to accommodate ongoing quality of life for people with dementia. It's a journey of caring enough to do the right thing and caring enough to do more.



Chapter 1: Dementia Care in Long-Term Care

Dementia care in long-term care continues to evolve, bringing with it new and higher expectations to improve quality of life and quality of care. There have been several significant strides and events toward the goal of improving how we manage our dementia care practices; however, a “gold standard” has yet to be established and because of this, 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 goal for dementia care that includes meeting needs beyond the activities of daily living, and into a more holistic person-centered framework of services. This manual will help you accomplish this goal.

The American Medical Directors Association (AMDA), dedicated to long-term care medicine, published clinical practice guidelines (*Dementia in the Long Term Care Setting – Clinical Practice Guideline*) for dementia care in nursing homes. The AMDA works closely

with 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 titled, “Overprescribed: The Human and Taxpayers’ Costs of Antipsychotics in Nursing Homes” (U.S. Senate, Special Committee on Aging, Washington, D.C., November 30, 2011). The hearing examined the use of antipsychotics among nursing home residents with dementia despite the U.S. Food and Drug Administration’s black box warnings for use, and discussed the need for safe and effective alternatives, citing increased risk of death when antipsychotics are used to treat the elderly who do not have a diagnosis of psychosis. An interdisciplinary approach to person-centered care was stressed for behavior management, while decreasing the use of unnecessary medication.

From a 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, Sections 1829 and 1919, that are requirements to include initial and ongoing dementia management training and abuse prevention training for nursing assistants.

A(i) 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.

In 2011, the Office of Inspector General (OIG) released a report, which indicated 83 % of nursing home residents did not have a proper diagnosis to justify the use of their antipsychotic medication. 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 underway 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, the AMDA also joined this partnership.

From a survey perspective, the CMS Center for Clinical Standards and Quality/Survey & Certification Group released a memorandum in May 2013 conveying clarifications for the survey process regarding dementia care and unnecessary drug use. Another memorandum was released in April 2014 regarding a focused survey process to assess dementia care and outlines five fundamental principles of dementia care:

- 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 have an evaluation 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 the use of individualized approaches as a first-line intervention (except in documented emergency situations or if clinically contraindicated) for BPSD. Utilizing a consistent process that focuses on a resident's individual needs and tries to understand behavior as a form of communication may help to reduce behavioral expressions of distress in some residents.
- 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 to discontinue these drugs.

Survey agencies will use, at a minimum, regulation F309 (Quality of Care) and F329 (Unnecessary Drugs) to investigate services for a resident with dementia. In May 2013, CMS issued a memorandum, 13-35-NH, for the *State Operations Manual* regarding dementia care. The update states that during the Entrance Conference in Task 2 of 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 the 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 those with dementia and antipsychotic use since their survey software will automatically identify the required survey sample. Included in the memorandum is a “Resident with Dementia Checklist” that may be used 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. This checklist can be found at the end of the *State Operations Manual* updates in the “SURVEY AND CERTIFICATION MEMORANDUM, S&C: 13-35-NH” issued May 24, 2013.

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 highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.

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 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.

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);
- Non-pharmacological interventions (such as behavioral interventions) are considered and used when indicated, instead of, or in addition to, medication;
- Clinically significant adverse consequences are minimized; and
- 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 Partnership, AMDA, and the surveyor guidance 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. If we work as an advocate and as a collaborative interdisciplinary team, utilizing the resources available to us, we can develop a gold standard of dementia care across the entire continuum of care that will change the culture of aging in our country and hopefully influence dementia care for the 35.6 million individuals around the world who are diagnosed with dementia.

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Adhere to the Centers for Medicare & Medicaid Services (CMS) dementia care initiative to reduce the use of antipsychotic medications in treating residents with dementia. This handbook will help the long-term care social services staff understand and address the challenging needs of residents with dementia at each stage of the disease's progression. Social services staff will benefit from the how-to guidance that breaks down CMS' initiative, and learn how to monitor the appropriate care of residents.

This book provides:

- Guidance on the use of non-pharmacological methods of reducing dementia-related behaviors
- Strategies for educating staff to provide assistance and assurance to residents' family members

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