



Guideline Summary NGC-9847

Guideline Title

Dementia in the long term care setting.

Bibliographic Source(s)

American Medical Directors Association (AMDA). Dementia in the long term care setting. Columbia (MD): American Medical Directors Association (AMDA); 2012. 47 p. [88 references]

Guideline Status

This is the current release of the guideline.

This guideline updates a previous version: American Medical Directors Association (AMDA). Dementia in the long-term care setting. Columbia (MD): American Medical Directors Association (AMDA); 2009. 48 p.

Scope

Disease/Condition(s)

Neurologic conditions with cognitive dysfunction, including:

- Alzheimer's disease
- Anoxic brain injury
- Creutzfeldt-Jacob disease
- Delirium*
- Human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS)-associated dementia
- Frontotemporal dementia
- Lewy body disease
- Multiple sclerosis
- Normal-pressure hydrocephalus
- Parkinson's disease
- "Parkinson's-plus" syndromes (e.g., frontotemporal dementia, Huntington's disease)
- Progressive supranuclear palsy
- Toxic dementias (e.g., lead poisoning, Wernicke-Korsakoff syndrome)
- Traumatic brain injury
- Vascular dementia

*Not all patients who experience delirium are or will be diagnosed with dementia. Patients with dementia, however, are at very high risk for the development of delirium.

Guideline Category

Diagnosis

Evaluation

Management

Risk Assessment

Treatment

Clinical Specialty

Family Practice

Geriatrics

Internal Medicine

Neurology

Nursing

Psychiatry

Intended Users

Advanced Practice Nurses

Allied Health Personnel

Dietitians

Nurses

Occupational Therapists

Pharmacists

Physician Assistants

Physicians

Social Workers

Speech-Language Pathologists

Guideline Objective(s)

- To offer practitioners and care providers in long term care (LTC) facilities a systematic approach to the recognition, assessment, treatment, and monitoring of patients with dementia, including impaired cognition and problematic behavior
- To provide a guide to appropriate management that maximizes function and quality of life, thereby minimizing the likelihood of complications and functional decline

Target Population

Elderly individuals and/or residents of long term care (LTC) facilities who have, or are suspected of having, dementia

Interventions and Practices Considered

Diagnosis/Assessment

1. Review of patient history
2. Review of current medications, including over-the-counter medications and herbal supplements
3. Evaluation of signs and symptoms of dementia
4. Assessment of patient's physical, functional, and psychosocial status
5. Assessment of patient's cognition, mood, and behavior
6. Diagnostic work-up, if appropriate
7. Determining if patient meets criteria for dementia
8. Identifying cause of dementia, if possible
9. Identifying patient's capabilities and deficits
10. Identifying triggers for disruptive behavior

Treatment/Management

1. Preparation of an interdisciplinary care plan
2. Optimizing function and quality of life and capitalizing on remaining strengths
 - Use of complementary and alternative therapies and dietary supplements
 - Medical interventions, if appropriate
3. Management of functional deficits
4. Addressing related ethical issues
5. Monitoring the patient's condition and adjusting management as appropriate

Major Outcomes Considered

- Level of functioning:
 - Functional assessment measures such as the Activities of Daily Living (ADL) portion of the Minimum Data Set (MDS), the Barthel Index, the Functional Activities Questionnaire (FAQ), or the Katz ADL scale
 - Cognitive function assessment measures such as the Blessed Orientation-Memory-Concentration Test, the Cognitive Performance Scale, the Clock Drawing Test, the Mini-Cog Diagnostic Test for dementia, the Mini-Mental State Examination (MMSE), the Montreal Cognitive Assessment Scale, the St. Louis University Mental Status Exam, or

State Examination (MIBSE), the Montreal Cognitive Assessment Scale, the St. Louis University Mental Status Exam, or the Verbal Fluency Test

- Signs and symptoms of dementia
- Quality of life
- Complications and functional decline

Methodology

Methods Used to Collect/Select the Evidence

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

The clinical practice committee vice-chair performs a systematic literature search for the topic of the guideline, using the electronic databases MEDLINE, PubMed, etc. Each year the Steering Committee reviews all American Medical Directors Association (AMDA) clinical practice guidelines that are 3 years old and commissions a thorough literature review to determine whether the content of each guideline remains current. If new literature does not change the content or scope of the original guideline, it is deemed to be current.

For this guideline revision, databases were searched between June 2009 and January 2011 for updated literature related to dementia in the long term care setting. Inclusion criteria included elderly, long term care, and dementia topics. The following search terms were used: elderly, long term care, nursing home, antipsychotics, delirium, behavior management, palliative care, advanced directives, dementia treatment, pharmacological management of dementia, anticholinergic, Cognitive Assessment Scales and instruments, Diagnostic Criteria for Dementia, BPSD, person-centered interventions for dementia.

Number of Source Documents

Not stated

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Quality of Evidence

The quality of evidence indicates the extent to which one can be confident that an estimate of effect is correct.

High: At least 1 randomized controlled trial OR 3 pre/post interventions or other prospective interventions or 3 well-structured, relevant observational studies

Moderate: Studies that use well-tested methods to make comparisons in a fair way, but where the results leave room for uncertainty (e.g., because of the size of the study, losses to follow-up, or the method used for selecting groups for comparison)

Low: Studies in which the results are doubtful because the study design does not guarantee that fair comparisons can be made

Methods Used to Analyze the Evidence

Review of Published Meta-Analyses

Systematic Review

Description of the Methods Used to Analyze the Evidence

Grading System for American Medical Directors Association (AMDA) Clinical Practice Guidelines

Judgments about the quality of evidence (see the "Rating Scheme for the Strength of the Evidence" field) require assessing the validity of results for important outcomes in individual studies. Explicit criteria should be used in making these judgments. In the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) Working Group approach, a systematic review of available evidence guides these judgments.

Sequential judgments are made concerning the following factors:

- The quality of evidence across studies for each important outcome
- Which outcomes are critical to a decision
- The overall quality of evidence across these critical outcomes
- The balance between benefits and harms
- The strength of recommendations

Reviewers consider four key elements: study design, study quality, consistency, and directness.

Definitions

Study design refers to the basic study design (broadly, observational studies and randomized trials).

Study quality refers to the detailed study methods and execution. Appropriate criteria are used to assess study quality for each important outcome. For randomized trials, for example, these criteria might include the adequacy of allocation concealment, blinding, and follow-up. Reasons for downgrading a quality rating must be explicit (e.g., failure to blind

concealment, blinding, and follow up. Reasons for downgrading a quality rating must be explicit (e.g., failure to blind patients and physicians reduced the quality of evidence for an intervention's impact on pain severity, a serious limitation).

Consistency refers to the similarity of effect estimates across studies. If there is important unexplained inconsistency in study results, confidence in the effect estimate for that outcome is reduced.

Directness refers to the extent to which the people, interventions, and outcome measures in the studies are similar to those of interest. For example, the directness of the evidence may be uncertain if the people of interest are older, sicker, or have more comorbidity than those in the studies. To determine whether important uncertainty exists, one can ask whether there is a compelling reason to expect important differences in the effect size. Because many interventions have more or less the same relative effects across most patient groups, reviewers should not use overly stringent criteria in deciding whether evidence is direct.

Criteria

Criteria for decreasing the grade:

- Serious (-1) or very serious (-2) limitation to study quality
- Important inconsistency (-1)
- Some (-1) or major (-2) uncertainty about directness
- Imprecise or sparse data (-1)
- High probability of reporting bias (-1)

Criteria for increasing the grade:

- Strong evidence of association: Significant relative risk greater than 2 (less than 0.5), based on consistent evidence from two or more observational studies, with no plausible confounders (+1)
- Very strong evidence of association: Significant relative risk greater than 5 (less than 0.2), based on direct evidence with no major threats to validity (+2)
- Evidence of a dose-response gradient (+1)
- All plausible confounders would have reduced the effect (+1)

These criteria are cumulative – e.g., if randomized controlled trials (RCTs) have serious limitations and there is uncertainty about the directness of the evidence, the grade of evidence would drop from high to low.

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

Original guidelines are developed by interdisciplinary workgroups, using a process that combines evidence- and consensus-based approaches. Workgroups include practitioners and others involved in patient care in long term care (LTC) facilities. Beginning with pertinent literature searches for articles and information related to the guideline subject and a draft outline/framework, each group works to develop a concise, usable guideline that is tailored to the LTC setting. Because scientific research in the LTC population is limited, many recommendations are based on findings from research involving community-living older adults. Some recommendations are based on the expert consensus opinion of practitioners and experts in the field of geriatric medicine.

The American Medical Directors Association (AMDA) Clinical Practice Guideline Steering Committee directs the guideline development and revision process. Each year the Steering Committee reviews all AMDA clinical practice guidelines that are 3 years old and commissions a thorough literature review to determine whether the content of each guideline remains current. The AMDA Clinical Practice Committee Chair selects the existing guidelines to be revised and new guidelines to be created based on 1) the Steering Committee's recommendations, 2) data collected, and 3) an assessment of the difficulty of development and relevance to the AMDA membership. AMDA's Board of Directors has final approval over this process.

Grading System for AMDA Clinical Practice Guidelines

The system AMDA has adopted for grading clinical practice guidelines (see the "Rating Scheme for the Strength of the Recommendations") is based on the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) Working Group Approach.

Sequential judgments are made concerning the following factors:

- The quality of evidence across studies for each important outcome
- Which outcomes are critical to a decision
- The overall quality of evidence across these critical outcomes
- The balance between benefits and harms
- The strength of recommendations

Rating Scheme for the Strength of the Recommendations

Strength of Recommendation

The strength of a recommendation indicates the extent to which one can be confident that adherence to the recommendation will do more good than harm.

- **Strong:** Benefits clearly outweigh risks.
- **Weak:** Benefits are balanced with risks.

- **Insufficient:** Evidence is inadequate to make a recommendation.

Cost Analysis

A formal cost analysis was not performed and published cost analyses were not reviewed.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

All American Medical Director Association (AMDA) clinical practice guidelines undergo external review. The draft guideline is sent to approximately 175+ reviewers. These reviewers include AMDA physician members and independent physicians, specialists, and organizations that are knowledgeable of the guideline topic and the long term care setting.

AMDA's guidelines are supported by the following associations/organizations, who are members of its Clinical Practice Guideline Steering Committee. These associations/organizations all have representatives who participate in the external review phase and officially sign off on the guideline before publication: American Association of Homes and Services for the Aging (now LeadingAge); American College of Health Care Administrators; American Geriatrics Society; American Health Care Association; American Society of Consultant Pharmacists; Gerontological Advanced Practice Nurses Association; Direct Care Alliance; National Association of Directors of Nursing Administration in Long Term Care; National Association of Health Care Assistants.

Recommendations

Major Recommendations

Note from the American Medical Directors Association (AMDA) and the National Guideline Clearinghouse (NGC): The original full-text guideline provides an algorithm on "Dementia in the Long Term Care Setting" to be used in conjunction with the written text. Refer to the "Guideline Availability" field for information on obtaining the algorithm, as well as the full text of the guideline, which provides additional details.

Levels of evidence (**High, Moderate, Low**) and grades of recommendation (**Strong, Weak, Insufficient**) are defined at the end of the "Major Recommendations" field.

Recognition

1. Review available information about the patient's recent or past physical, functional, cognitive, and behavioral status. Look for previous diagnoses in which dementia is a key symptom. (**Quality of Evidence: Moderate; Strength of Recommendation: Strong**)
2. Check current medical orders for medications that can alter cognitive function (e.g., antiarrhythmics, opioids, hypnotics, psychotropics, sedatives, medications with significant anticholinergic properties). Also ask about the use of over-the-counter medications or herbal preparations that may affect cognitive function. (**Quality of Evidence: Low; Strength of Recommendation: Strong**)
3. Search for evidence of specific impairments or symptoms (e.g., neurologic or behavior symptoms) that may suggest underlying dementia. (**Quality of Evidence: Moderate; Strength of Recommendation: Strong**)
4. Professional staff should observe the patient's current physical, functional, and psychosocial status. (**Quality of Evidence: Low; Strength of Recommendation: Strong**)

Assessment

5. Assess the patient's cognition, mood, and behavior using a validated tool, such as items in the Minimum Data Set (MDS) 3.0 instrument. (**Quality of Evidence: Moderate; Strength of Recommendation: Strong**)
6. Decide if further workup is useful and appropriate. (**Quality of Evidence: Moderate; Strength of Recommendation: Weak**)
7. Evaluate if the patient meets the criteria for a diagnosis of dementia (**Quality of Evidence: Low; Strength of Recommendation: Strong**).
8. Consider consultation with appropriate specialists for neuropsychiatric evaluation and testing if basic workup and testing do not enable adequate assessment of the patient's conditions, identification of the causes of the patient's symptoms, or proper management. Formal neuropsychological testing may also be helpful when the results of screening tests are inconsistent with clinical observations of the degree and type of cognitive impairment. Neuropsychological testing also has the benefit of being able to identify the patient's cognitive assets and weaknesses. (**Quality of Evidence: Low; Strength of Recommendation: Strong**)
9. Soon after admission or a significant condition change, assess the patient's capabilities in various domains. (**Quality of Evidence: Low; Strength of Recommendation: Strong**)
10. Prognostication is important in the long term care (LTC) setting for appropriate care planning and timely use of available resources. Prognostication is not a guarantee of future events but rather an estimate of what can reasonably be expected. Prognostication of dementia is challenging; evidence supports using age, decline in functional status and oral intake, and increasing dependence in activities of daily living (ADLs) as the most important features in determining prognosis in end-stage dementia. (**Quality of Evidence: Moderate; Strength of Recommendation: Strong**)
11. Identify triggers for disruptive behaviors. Do not assume that a behavior is triggered by environmental or other nonmedical factors until alternate causes have been considered. This is especially important when patients are newly admitted, have recently been hospitalized, or have a significant change of condition. (**Quality of Evidence: Low; Strength of Recommendation: Strong**)

Treatment/Intervention

12. Prepare an individualized interdisciplinary care plan that defines treatment goals that are appropriate for the individual patient, taking into account the wishes of the patient and/or family; incorporates definite, measurable objectives derived from those treatment goals and; allows for modification as the patient's needs change. (**Quality of Evidence: Low; Strength of Recommendation: Strong**)

13. Optimize the patient's function and quality of life utilizing specialized environment, trained caregiver staff, and activity programs in special care units. (**Quality of Evidence: Moderate; Strength of Recommendation: Strong**)

14. Consider the use of complementary and alternative methods and dietary supplements. (**Quality of Evidence: Low; Strength of Recommendation: Weak**)

15. Consider medical interventions if appropriate. (**Quality of Evidence: High; Strength of Recommendation: Strong**)

16. Manage functional deficits. A restorative nursing program may help to optimize the function of a patient who has impaired cognition and behavior. Practitioners should help to identify patients who are likely to benefit from such interventions and authorize appropriate evaluations and management. (**Quality of Evidence: Low; Strength of Recommendation: Strong**)

17. Address ethical issues. Facilities should develop policies and procedures or guidelines for managing issues such as attempted sexual activity between two cognitively impaired patients or between a cognitively impaired and a cognitively intact patient. The facility should have a systematic, consistent process for managing ethical issues and documenting patient wishes. The practitioner should help to define the potential benefits and burdens of treatments for the patient with dementia, clarify the patient's prognosis, and support decision making by families or surrogates. The practitioner should review the relevance and appropriateness to the patient's overall care various treatment recommendations made by other disciplines or consultants. (**Quality of Evidence: Low; Strength of Recommendation: Strong**)

Good evidence exists that artificial nutrition does not materially prolong life or improve quality of life in patients with advanced dementia. Substantial functional decline and recurrent or progressive medical illnesses may indicate that a patient who is not eating is unlikely to obtain any significant or long term benefit from artificial nutrition and hydration. (**Quality of Evidence: Moderate; Strength of Recommendation: Strong**)

Monitoring

18. Monitor the patient's condition and adjust management as appropriate. (**Quality of Evidence: Low; Strength of Recommendation: Strong**)

19. Monitor the facility's management of dementia (**Quality of Evidence: Moderate; Strength of Recommendation: Insufficient**)

Definitions:

Quality of Evidence

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Strength of Recommendation

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- **Strong:** Benefits clearly outweigh risks.
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- **Insufficient:** Evidence is inadequate to make a recommendation.

Clinical Algorithm(s)

An algorithm for dementia in the long term care setting is provided in the original guideline document.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of supporting evidence is identified and graded for each recommendation (see the "Major Recommendations" field).

The guideline was developed by an interdisciplinary workgroup, using a process that combined evidence- and consensus-based approaches. Because scientific research in the long term care population is limited, many recommendations are based on findings from research involving community-living older adults. Some recommendations are based on the expert consensus opinion of practitioners and experts in the field of geriatric medicine.

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Implementation of this guideline should help long term care facilities to improve their ability to:

- Identify patients who are at risk for new or progressive dementia
- Differentiate among neurological, physical, psychiatric, and environmental causes of behavioral symptoms
- Manage dementia symptoms, consequences, and complications effectively and appropriately
- Identify the nature and causes of dementia in different patients
- Identify and manage potential sources of excess disability
- Minimize preventable complications and functional decline
- Respond appropriately to the changing needs of patients with dementia
- Make appropriate environmental and staffing modifications to maximize patient dignity, comfort, and safety
- Improve the understanding of staff, family members, and caregivers about dementia and respond appropriately to their concerns

As a result of these improvements in process, the following patient-related outcomes may be anticipated:

- Optimized function and quality of life
- Reduced complications and negative consequences of the condition or its management
- Improved resource utilization

Potential Harms

Examples of complications from medical treatment of problematic behavior and impaired cognition:

- Adverse drug effects and interactions
- Cardiac arrhythmias
- Sudden cardiac death
- Increased lethargy or confusion
- Stroke
- Falls
- Metabolic abnormalities
- Orthostatic hypotension
- Worsening of disruptive or socially unacceptable behavior

Table 18 in the original guideline documents lists adverse effects of commonly used cholinesterase inhibitors.

Qualifying Statements

Qualifying Statements

- This clinical practice guideline is provided for discussion and educational purposes only and should not be used or in any way relied upon without consultation with and supervision of a qualified physician based on the case history and medical condition of a particular patient. The American Medical Directors Association (AMDA), its heirs, executors, administrators, successors, and assigns hereby disclaim any and all liability for damages of whatever kind resulting from the use, negligent or otherwise, of this clinical practice guideline.
- The utilization of AMDA's Clinical Practice Guideline does not preclude compliance with State and Federal regulation as well as facility policies and procedures. They are not substitutes for the experience and judgment of clinicians and caregivers. The Clinical Practice Guidelines are not to be considered as standards of care but are developed to enhance the clinician's ability to practice.
- AMDA guidelines emphasize key care processes and are created to be used in conjunction with facility-specific policies and procedures that guide staff and practitioner practices and performance. They are meant to be used in a manner appropriate to the population and practice of a particular facility. Guideline implementation may be affected by resources available in the facility, including staffing, and will require the involvement of all those in the facility who have a role in patient care.
- Long term care facilities care for a variety of individuals, including younger patients with chronic diseases and disabilities, short-stay patients needing postacute care, and very old and frail individuals suffering from multiple comorbidities. When a workup or treatment is suggested, it is crucial to consider if such a step is appropriate for a specific individual. A workup may not be indicated if the patient has a terminal or end-stage condition, if it would not change the management course, if the burden of the workup is greater than the potential benefit, or if the patient or his or her legally authorized representative would refuse treatment. It is important to carefully document in the patient's medical record the reasons for decisions not to treat or perform a workup or for choosing one treatment approach over another.

Implementation of the Guideline

Description of Implementation Strategy

The implementation of this clinical practice guideline (CPG) is outlined in four phases. Each phase presents a series of steps, which should be carried out in the process of implementing the practices presented in this guideline. Each phase is

steps, which should be carried out in the process of implementing the practices presented in this guideline. Each phase is summarized below.

I. **Recognition**

- Define the area of improvement and determine if there is a CPG available for the defined area. Then evaluate the pertinence and feasibility of implementing the CPG

II. **Assessment**

- Define the functions necessary for implementation and then educate and train staff. Assess and document performance and outcome indicators and then develop a system to measure outcomes

III. **Implementation**

- Identify and document how each step of the CPG will be carried out and develop an implementation timetable
- Identify individual responsible for each step of the CPG
- Identify support systems that impact the direct care
- Educate and train appropriate individuals in specific CPG implementation and then implement the CPG

IV. **Monitoring**

- Evaluate performance based on relevant indicators and identify areas for improvement
- Evaluate the predefined performance measures and obtain and provide feedback

Table 26 in the original guideline document provides sample performance measurement indicators (process indicators and outcome indicators).

Implementation Tools

Audit Criteria/Indicators

Clinical Algorithm

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

End of Life Care

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Safety

Identifying Information and Availability

Bibliographic Source(s)

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Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

1998 (revised 2012)

Guideline Developer(s)

American Medical Directors Association - Professional Association

Guideline Developer Comment

Organizational participants included:

- American College of Health Care Administrators
- American Geriatrics Society
- American Health Care Association
- American Society of Consultant Pharmacists
- Direct Care Alliance
- Gerontological Advanced Practice Nurses Association
- LeadingAge

- National Association of Directors of Nursing Administration in Long Term Care
- The AMDA Foundation

Source(s) of Funding

American Medical Directors Association

Guideline Committee

Clinical Practice Guideline Steering Committee

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Financial Disclosures/Conflicts of Interest

All contributors must submit an Accreditation Council for Continuing Medical Education (ACCME) approved disclosure form prior to being accepted as a volunteer member of the guideline workgroup. This disclosure form is reviewed by the chair of the American Medical Directors Association (AMDA) Clinical Practice Committee. If any conflicts are perceived, that person is not accepted to be part of the workgroup.

Guideline Status

This is the current release of the guideline.

This guideline updates a previous version: American Medical Directors Association (AMDA). Dementia in the long-term care setting. Columbia (MD): American Medical Directors Association (AMDA); 2009. 48 p.

Guideline Availability

Electronic copies: Not available at this time.

Print copies: Available from the American Medical Directors Association, 10480 Little Patuxent Pkwy, Suite 760, Columbia, MD 21044. Telephone: (800) 876-2632 or (410) 740-9743; Fax (410) 740-4572. Web site: www.amda.com.

Availability of Companion Documents

Table 26 in the original guideline document provides sample performance measurement indicators (process indicators and outcome indicators).

Patient Resources

None available

NGC Status

This summary was completed by ECRI on July 12, 1999. The information was verified by the American Medical Directors Association as of August 8, 1999. This NGC summary was updated by ECRI on August 26, 2005. This summary was updated by ECRI Institute on July 25, 2008, following the U.S. Food and Drug Administration advisory on Antipsychotics. This summary was updated by ECRI Institute on November 1, 2010. The updated information was verified by the guideline developer on December 21, 2010. This NGC summary was updated on August 9, 2013. The updated information was verified by the guideline developer on September 27, 2013.

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