



National Hospice and Palliative Care Organization
Palliative Care Resource Series

**PALLIATIVE CARE FOR DEMENTIA
PATIENTS: PRACTICAL TIPS FOR
HOME BASED PROGRAMS**

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PALLIATIVE CARE FOR DEMENTIA PATIENTS: THE NEED

Alzheimer's dementia is the most common type of dementia. In 2015, 5.3 million Americans were estimated to be suffering from Alzheimer's dementia. This number is expected to triple by 2050. One in 3 seniors dies of dementia and Alzheimer's disease is the 6th leading cause of death (1).

Other common dementias include vascular, frontotemporal and Lewy body dementia. These can occur in combination with Alzheimer's disease. Although there are additional rare causes of dementia, this paper will focus on the more frequently encountered ones. A table is included at the end of the paper which describes types of dementia, distinguishing features and important considerations.

DEFINITION AND PREVALENCE OF DEMENTIA

Dementia is a syndrome involving decline in memory, thinking, behavior and the ability to perform daily activities (2). Although Alzheimer's dementia is not commonly seen in persons below the age of 60, its prevalence is 30-50% by age 85 (3). It is not considered a normal part of aging rather it is a true disease state.

RELEVANT PATHOPHYSIOLOGY

Alzheimer's dementia is characterized by the development of extracellular amyloid plaques (beta amyloid), intracellular neurofibrillary tangles (due to tau protein, synaptic deterioration and neuronal death) (4). Genetic factors are implicated, but complicated, and do not reflect the majority of Alzheimer's cases.

- *Vascular dementia* is a form of dementia closely associated with cardiovascular disease. Some of the risk factors can be modified, as seen with long term hypertension (blood pressure) control.
- *Frontotemporal dementia* is characterized by atrophy of the frontal and temporal lobes of the brain due to abnormal protein inclusions in the neurons.
- *Lewy body dementia* is associated with the development of "Lewy Bodies" (alpha-synuclein) in the cytoplasm of neurons in the brain. It is commonly associated with Parkinsonian like symptoms but is not actual Parkinson's Disease.

In the late presentations of dementia it may be difficult to distinguish between the different types of dementia.

DIAGNOSIS

Dementia is a diagnosis of exclusion. Diagnosis requires exclusion of potentially treatable conditions including depression, hypothyroidism, vitamin B12 deficiency, electrolyte abnormalities, neurosyphilis and normal pressure hydrocephalus.

The use of medications with anticholinergic, amnestic, or sedative side effects can also cause symptoms of dementia. Definitive diagnosis is possible only by autopsy. Clinical history, along with the mental status tests and other investigations can aid in identifying the type of dementia and developing a treatment plan.

Dementia is suspected when the following are reported: forgetfulness, disorientation and change in behaviors or routine. This is followed by mental status tests, most commonly the mini-mental state exam (MMSE). Lab tests and imaging studies may be ordered if required.

MMSE Scores

SCORE	LIKELY ASSOCIATION WITH SEVERITY OF DEMENTIA
24-30	Normal
20-23	Mild cognitive impairment*
10-19	Moderate cognitive impairment
<10	Severe cognitive impairment

*Not all patients progress to have dementia
These scores can vary by age and education. Reference table should be used.

CLINICAL FEATURES

Dementia is a progressive, incurable and irreversible syndrome. The Functional Assessment Staging of Alzheimer's Disease (FAST) is a helpful scale used to evaluate patients as they move through the different stages of dementia. Information should be collected from the patient if possible and then corroborated with a caregiver or family member. The FAST scale is included on [page 9](#) of this paper.

DISEASE MANAGEMENT

Pharmacologic Therapies Medications targeted at slowing down the disease process have moderate effects at best. These medications include cholinesterase inhibitors and memantine. There is no evidence to support the use of these medications in patients with end stage dementia (e.g. those at stage 7 on the FAST scale).

Medications targeted at treating problematic agitation behaviors in advanced dementia include antipsychotic medications that are often ineffective or can worsen other types of dementia like Lewy Body dementia (5). A 2005 meta-analysis of placebo-controlled trials showed an increased risk of death with the use of atypical antipsychotics. This led to a black-box warning issued by the Food and Drug Administration regarding the use of these agents in patients with dementia (6).

Non-pharmacologic Therapies for the treatment of behavioral symptoms for dementia include cognitive/emotion-orientation interventions; sensory stimulation; behavioral management techniques; and exercise therapy.

- Literature suggests that sensory stimulations approaches such as light therapy, aroma therapy and massage/touch therapy show greater promise than emotion-oriented approaches such as reminiscence and validation.
- Pet therapy has been demonstrated to decrease agitated and disruptive behaviors and improve social and verbal interactions but more rigorous studies are needed.
- Behavioral management techniques include functional analysis of specific behaviors, habit training, progressive muscle relaxation, communication training, behavioral or cognitive-behavioral therapy, and various types of individualized behavioral reinforcement strategies. There is some evidence to suggest these are effective strategies to reduce behavioral symptoms.
- Lastly, exercise therapy increases sleep time in patients with dementia although other outcomes such as a reduction in agitation from exercise therapy are not as robust (7).

Pain Pain can be difficult to assess in patients with advanced dementia and hence is under recognized and undertreated. A trial of pain medication is always the first step to treating agitation and other problematic behaviors of dementia (8).

Drugs of questionable benefit should be discontinued in advanced dementia unless they align with the goals of care (9).

- Medications such as statins and cholinesterase inhibitors are considered not clinically beneficial in patients with advanced dementia.
- Benzodiazepines and anticholinergics should be avoided in the elderly as they can precipitate delirium.
- Haloperidol should be avoided in patients with Lewy body dementia.

PALLIATIVE CARE IN DEMENTIA PATIENTS AT HOME

Initially, the functional status of a dementia patient declines steadily until it reaches a poor and dependent condition. During this period any subtle change in the patient's health can result in significant changes in mental status including increased confusion, lethargy, or agitation. Maintaining a peaceful environment can help calm patients with dementia and is often best achieved in the comfort of their own home surrounded by familiar people.

Providing care at home can be stressful for caregivers due to factors such as the need for constant supervision and the emotional strain caused by the patient's personality changes. Providing education and guidance to caregivers can decrease caregiver burden, increase patient's quality of life, and avoid inappropriate admissions to the hospital.

The delivery of this type of care requires intensive planning and care coordination between all involved medical specialties as well as with family/caregivers/psychosocial supports. The team involved with this care may include Palliative Care, Primary Care, Geriatrics, and additional community partners depending on local availability such as Home Care, Parish Nurses and the Area Agency on Aging.

The disease trajectory and advance care planning need to be discussed with the patient and surrogate decision maker(s) early in the disease. This is to ensure patients' participation in decisions that will need to be made as the disease progresses. Early discussions also help the surrogate decision maker(s) role when the patient is unable to make decisions.

CLINICAL

Areas of special focus on initial and subsequent visits at home (may depend on the frequency of visits):

Ideally the initial visit should involve all palliative care team members with attention to:

1. Physical Signs and Symptoms

■ Vital signs

Pain is often under diagnosed in dementia patients due to communication barriers. Ask the patient simple questions and utilize a modified pain rating scale: such as the faces scale. If the patient is not able to participate, evaluate non-verbal cues and interview the caregivers/family to determine a pattern (10).

■ Physical exam

Patients with dementia may become frightened or agitated during the physical exam. Explain your actions, provide reassuring touch, and approach in a calm manner. Utilize family members during the exam to offer reassurance or to distract the patient.

■ Functional status: use one tool consistently such as the Palliative Performance Scale (PPS).

Include evaluation of the individual elements of the patient's functional status:

- ◆ Sleep patterns: *patients with dementia often reverse their days and nights creating sleepless nights for the caregivers.*
- ◆ Skin integrity: *poor nutrition, incontinence, and bed bound status place patients at risk.*

- ◆ Malnutrition: *monitor dysphagia and weight loss, including ability to swallow medications. Recommend small, frequent meals with soft, finger foods. Eventually this may lead to discussions regarding burdens and benefits of PEG tube placement.*
- ◆ Incontinence: *scheduled and frequent toileting may help delay incontinence. Once incontinent, instruct caregivers to clean patient frequently to avoid skin breakdown.*
- ◆ Falls: *monitor for fall risk and safety issues including wandering.*
- Screen for symptoms including memory loss if patient is able to participate: use one tool consistently. The following tools are recommended:
 - ◆ Edmonton Symptom Assessment Scale (ESAS) *Symptoms are missed if a screening tool is not used.*
 - ◆ MMSE or Saint Louis University Mental Status (SLUMS) for monitoring progression of memory loss (11, 12). RUDAS can be the best scale for patients with little or no education or patients from a different ethnic or cultural background (13).
- Medication reconciliation
 - ◆ Review and determine benefits/burdens of each medication. *Discontinue or taper medications that no longer provide any benefit or that may result in more harm due to side effects. Refer to BEERS list (14).*
 - ◆ Review how each medication is dispensed with patient/caregiver. *Assess ability to manage medications, and ensure a clear understanding of importance and purpose of each.*
- Interview family members and caregivers to determine a baseline functional level and to understand the patient's unique patterns. It is essential to work with family to help identify significant changes.

2. Additional needs assessments:

- Emotional/financial support screening
Request social worker follow up, if needed, in addition to routine social worker visits.
- Spiritual needs screening
Request chaplain visit, if needed, in addition to routine chaplain visits.
- Home Safety evaluation
Including but not limited to placing medications in lock box, turning off stove, and installing locks on doors to prevent wandering patients from leaving the home.
- Caregiver screening
Ensure social worker and chaplain support to caregiver(s). Monitor for burn out.
 - ◆ It is vital to optimize all support to the patient and the caregiver from the time of initiation of the program. *All community resources need to be well known to the team to be able to connect them with the patient and caregivers.*
 - ◆ Education and support is crucial to help caregivers optimize the patient's quality of life and safety. *Offer support groups, both local and online, as well as written resources such as "The 36 Hour Day" (15).*
 - ◆ Offer respite. *This includes day care, or temporary stays in nursing homes.*

3. Patient goals

- Care plan and patient goals should be reviewed frequently with the patient and caregiver to ensure the treatment provided matches the patient's goals. The family should always be involved in these discussions as they will become the patient's advocate as the disease progresses. Make sure they have a clear understanding of the disease process and the expected trajectory and outcomes.
- If the patient is still competent, he/she should complete an advance directive/ Physician Orders for Life Sustaining Treatment (POLST). Any changes in goals should be promptly reflected in the documents.
These documents should be readily available to the patient, caregiver and paramedics (if called). Many programs have these placed on the refrigerator as recommended by Emergency Medical Services (EMS).
- Issues around nutrition and hydration can be very sensitive for family members and decisions require skillful discussions and decision making. Assistance with feeding patients orally is the preferred approach with emphasis on quality of life (16). Studies suggest no survival advantage to placement of PEG tubes. PEG tubes are of no benefit in preventing aspiration in patients with advanced dementia. Their placement for nourishment can lead to the increased use of chemical and physical restraints.
- Depending on the clinical status, treatment options and goals should be readdressed on a regular basis. This would include informing the patient and the caregiver about hospice as he/she becomes eligible.
- Use Functional Assessment Scale (FAST) scale to help determine prognosis and hospice eligibility (17).

4. Review and education

- Any changes in the treatment plan should be given to the patient and caregiver in writing and reviewed with them during the visit. Include specific instructions regarding a proactive plan, detailing which medical service to call when changes occur or in an emergency.
A good practice is to ask the patient/caregiver to repeat back the plan.
- Educate caregivers. This reduces caregiver stress and optimizes patient's quality of life. For example:
 - ◆ REDIRECT instead of correcting the patient.
 - ◆ Appropriate patient stimulation including triggers to help the patients perform basic activities. *Music and art therapy, pictures of the past, simple/familiar activities.*
 - ◆ How to cope with personality changes and emotionally charged situations.
- Before leaving the patients' residence, patients and/or caregivers should be instructed to call the palliative care service, when available, with any questions or concerns. Ensure they have the number and review the backup plan when the palliative care service is not available.
 - ◆ *Ideally, a call to the PCP/Geriatrics should be made from the patient's home during every visit and the plan of care should be reviewed.*

OPERATIONAL

Patients with complex chronic illnesses require a team approach. Scope of practice of each member of the team should be delineated up front. Routine Interdisciplinary Team (IDT) meetings and communication with the other specialists are essential.

Role delineation is vital when working in the home. Prior to launch of the service it is recommended to meet with your primary care colleagues and the Geriatrics team you will be working with to establish parameters.

A strong relationship with Geriatrics and Primary care is essential. Care coordination is best accomplished with strong communication between all specialties. Operational communication is also vital to discuss changes such as protocols and practice personnel.

A working relationship with the family/caregivers is critical for success. Patients with dementia rely on their family members to advocate for their wishes and values. In addition, the family/caregivers know the unique patterns of their loved one, which will help optimize treatment.

Care of the family/caregiver is part of caring for the patient. Caregiver burnout is a serious consequence of dementia. Assessment includes involving appropriate supportive resources and determining the caregiver's ability to care for the patient in the home. This includes possible referral to agencies to assist with caregiver responsibilities, to day care programs, or to designated dementia units at skilled nursing facilities.

Operational policies are required to guide caregivers in emergencies. A strategy of how to handle emergencies should include providing written plans to caregivers. If your service is not 24/7, an off-work hours plan needs to be in place.

Quality data should be collected and reviewed routinely.

- Clinical and operational data, number and length of hospitalizations, patient/family satisfaction and referring entity satisfaction.
- Expected outcomes: improved continuity and quality of care, decrease in ER visits and inappropriate hospitalizations, increased adherence to patient goals, improved patient and provider satisfaction.

SUMMARY: LESSONS LEARNED AND BEST PRACTICES

- A well-coordinated team is needed. It is preferable to have a shared electronic medical record to streamline communication.
- Frequent team meetings allow other providers to offer insights and techniques. Creativity may be required to develop a successful care plan.
- Each home setting is unique. Home visits offer insight into the patient's values, barriers, and needs. Helping to eliminate obstacles for patients is critical in order to improve the quality of life for both the patient and the caregiver. Respect for the home environment is essential.
- Focus should be on keeping the patient comfortable and meeting patient/family goals, versus avoiding hospitalizations. Some hospitalizations may be appropriate.
- Proactive plans are vital to avoid crises. Use creative solutions with each unique situation.
- Active listening offers comfort and provides insight into the patient/caregivers main concerns.
- Efficiencies are obtained through having an adequate number of support staff trained in palliative care to work with the palliative care provider(s). Having support staff that triage phone calls, provide clinical input, assist with care coordination and manage referrals maximizes the provider's time.
- Relationships develop in a different way when in the home; resiliency and self-care must be part of this work.

TYPE OF DEMENTIA	DISTINGUISHING FEATURE	IMPORTANT CONSIDERATIONS
Alzheimer's Dementia	Slow onset	Increased prevalence with aging
Vascular Dementia	Usually associated neurological deficits	Closely associated with cardiovascular disease
Frontotemporal Dementia	Changes in personality typically marked by disinhibition	Common cause of dementia in younger patients
Lewy Body Dementia	Features overlap with Parkinson's disease Hallucinations are common	Haloperidol and chlorpromazine to be avoided

FUNCTIONAL ASSESSMENT STAGING (FAST)

Instructions

The **FAST Stage** is the highest consecutive level of disability. For clinical purposes, in addition to staging the level of disability, additional, non-ordinal (nonconsecutive) deficits should be noted, since these additional deficits are of clear clinical relevance.

For the purpose of therapeutic trials, the FAST can be used to sensitively encompass the full range in functional disability in CNS aging and dementia. For these purposes the **FAST Disability Score** should be obtained as follows:

- (1) Each FAST substage should be converted into a numerical stage. Specifically, the following scoring should be applied: 6a=6.0; 6b=6.2; 6c=6.4; 6d = 6.6; 6e = 6.8; 7a = 7.0; 7b=7.2; 7c=7.4; 7d=7.6; 7e=7.8; 7f=8.0.
- (2) The consecutive level of disability (FAST stage) is scored and given a numerical value.
- (3) The non-consecutive FAST deficits are scored. A non-consecutive full stage deficit is scored as 1.0. A non-consecutive sub - stage deficit is scored as 0.2.
- (4) **The FAST Disability Score** =(The FAST Stage Score) + (Each Non-Consecutive FAST disability scored as described).

For example, if a patient is at FAST Stage 6a, then the patient's FAST stage score = 6.0. By definition, this patient cannot handle a job, manage their personal finances, independently pick out their clothing properly, or put on their clothing properly without assistance. If, in addition, this patient is incontinent of urine and cannot walk without assistance, then nonconsecutive deficits "6d" and "7c" are scored. **The FAST Disability Score** for this patient is 6.0 + 0.2+0.2 = 6.4.

Functional Assessment Staging (FAST) 1, 2 (Check highest **consecutive** level of disability.)

1. **No difficulty**, either subjectively or objectively.
2. Complains of forgetting location of objects. **Subjective work difficulties.**
3. Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. **Decreased organizational capacity.***
4. **Decreased ability to perform complex tasks**, e.g., planning dinner for guests, handling personal finances (such as forgetting to pay bills), difficulty marketing, etc.*
5. **Requires assistance in choosing proper clothing** to wear for the day, season, or occasion, e.g. patient may wear the same clothing repeatedly, unless supervised.*
6. (a) **Improperly putting on clothes without assistance or cuing** (e.g., may put street clothes on over night clothes, or put shoes on wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks.*
(b) Unable to bathe properly (e.g., **difficulty adjusting bath-water temperature**) occasionally or more frequently over the past weeks.*

- (c) **Inability to handle mechanics of toileting** (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.*
 - (d) **Urinary incontinence** (occasionally or more frequently over the past weeks).*
 - (e) **Fecal incontinence** (occasionally or more frequently over the past weeks).*
7. (a) Ability to speak limited to approximately **a half a dozen intelligible different words or fewer**, in the course of an average day or **in the course of an intensive interview**.
- (b) Speech ability limited to the use of **a single intelligible word** in an average day or **in the course of an intensive interview** (the person may repeat the word over and over).
 - (c) Ambulatory ability lost (**cannot walk without personal assistance**).
 - (d) **Cannot sit up without assistance** (e.g., the individual **will fall over if there are no lateral rests [arms] on the chair**).
 - (e) **Loss of ability to smile**.
 - (f) **Loss of ability to hold up head independently**.

* Scored primarily on the basis of information obtained from a knowledgeable informant and/or caregiver.

1 Reisberg, B., Functional assessment staging (FAST). Psychopharmacology Bulletin, For further information and permission for usage, contact Barry Reisberg, M.D., at barry.reisberg@nyumc.org 1988;24:653-659.

2 Copyright © 1984 by Barry Reisberg, M.D. All rights reserved.FUNCTIONAL ASSESSMENT STAGING (FAST)

REFERENCES

1. Alzheimer's Association. 2015 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia* 2015;11(3):332+. Retrieved December 28, 2015, from <http://www.alz.org/facts/>
2. World Health Organization. Dementia Fact Sheet No. 362. March 2015. Retrieved December 28, 2015, from <http://www.who.int/mediacentre/factsheets/fs362/en/>
3. Thies W, Bleiler L. Alzheimer's disease facts and figures. *Alzheimers Dement* 2011;7:208–244.
4. Alzheimer A, Stelzmann RA, Schnitzlein HN, Murtagh FR. An English translation of Alzheimer's 1907 paper, "Über eine eigenartige Erkrankung der Hirnrinde". *Clin Anat.* 1995;8(6):429-31.
5. Sink, K. M., Holden, K. F., & Yaffe, K. Pharmacological treatment of neuropsychiatric symptoms of dementia: a review of the evidence. *JAMA* 2005;293(5), 596-608.
6. Schneider LS, Dagerman KS, Insel P. Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *JAMA* 2005;294:1934-43.
7. O'Neil ME, Freeman M, Christensen V, Telerant R, Addleman A, Kansagara D. A Systematic Evidence Review of Non-pharmacological Interventions for Behavioral Symptoms of Dementia [Internet]. Washington (DC): Department of Veterans Affairs; 2011 Mar. Retrieved December 28, 2015, from http://www.ncbi.nlm.nih.gov/books/NBK54971/pdf/Bookshelf_NBK54971.pdf
8. Hendriks SA, Smalbrugge M, Hertogh CM, van der Steen JT. Dying with dementia: symptoms, treatment, and quality of life in the last week of life. *J Pain Symptom Manage* 2014;47:710-20.
9. Holmes HM, Sachs GA, Shega JW, Hougham GW, Cox Hayley D, Dale W. Integrating palliative medicine into the care of persons with advanced dementia: identifying appropriate medication use. *J Am Geriatr Soc* 2008;56:1306-11.
10. Wilner LS, Arnold RM. Fast Facts and Concepts #126. Pain Assessment in the Cognitively Impaired. April 2009. Retrieved December 28, 2015, from <https://www.capc.org/fast-facts/>
11. Retrieved December 28, 2015, from https://www.alz.org/national/documents/brochure_tools_foridassesstreat.pdf
12. SH Tariq, N Tumosa, JT Chibnall, HM Perry III, and JE Morley. The Saint Louis University Mental Status (SLUMS) Examination for Detecting Mild Cognitive Impairment and Dementia is more sensitive than the Mini-Mental Status Examination (MMSE) - A pilot study. *J Am Geriatr Psych* (in press). Retrieved December 28, 2015, from http://medschool.slu.edu/agingsuccessfully/pdf/surveys/slumsexam_05.pdf
13. Basic D, Khoo A, Conforti DA, Rowland JT, Vrantsidis F, LoGiudice D, Hill K, Harry J, Lucero K, Prowse RJ. Rowland Universal Dementia Assessment Scale, Mini Mental State Examination and General Practitioner Assessment of Cognition in a multicultural cohort of community-dwelling older persons with early dementia. *Australian Psychologist* 2009;44: 40-53.

14. Campanelli CM. American Geriatrics Society Updated Beers Criteria for Potentially Inappropriate Medication Use in Older Adults: The American Geriatrics Society 2012 Beers Criteria Update Expert Panel. *Journal of the American Geriatrics Society* 2012;60(4):616-631.
15. Mace, N. L., & Rabins, P. V. (1991). *The 36-hour day: A family guide to caring for persons with Alzheimer's disease, related dementing illnesses, and memory loss in later life*. Baltimore: The Johns Hopkins University Press.
16. American Academy of Hospice and Palliative Medicine. Percutaneous feeding tubes in patients with dementia. February 21, 2013. Retrieved December 28, 2015, from <http://www.choosingwisely.org/clinician-lists/american-academy-hospice-palliative-care-percutaneous-feeding-tubes-in-patients-with-dementia/>
17. Tsai, S, Arnold RM. Fast Facts and Concepts #150. Prognostication in Dementia. April 2009. Retrieved December 28, 2015, from <https://www.capc.org/fast-facts/>
18. Sekerak RJ, Stewart JT. Caring for the patient with end stage dementia. *Ann Longterm Care*. 2014 Dec; 22(12). Retrieved December 28, 2015, from <http://www.annalsoflongtermcare.com/article/caring-patient-end-stage-dementia>