

# End of Life Care for Dementia Patients

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## Objectives

- Understand that dementia is a terminal illness
- Identify barriers to adequate symptom management in dementia patients
- Understand Hospice admission criteria for dementia as a terminal diagnosis
- Identify Hospice goals for dementia patients
- Understand characteristic problems associated with advanced dementia patients
- Understand interventions that are helpful in the end of life care of dementia patients
- Identify alternative pain assessment tools in the dementia patient

## What is Dementia

- A general term that describes a brain syndrome characterized by problems with memory, judgment, language, orientation, and executive functioning.

## Most Common Types of Dementia

- Alzheimer's Dementia
- Vascular Dementia
- Lewy Body Dementia

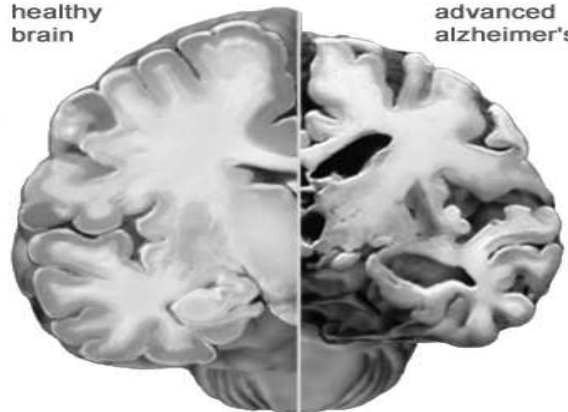
## Alzheimer's Dementia

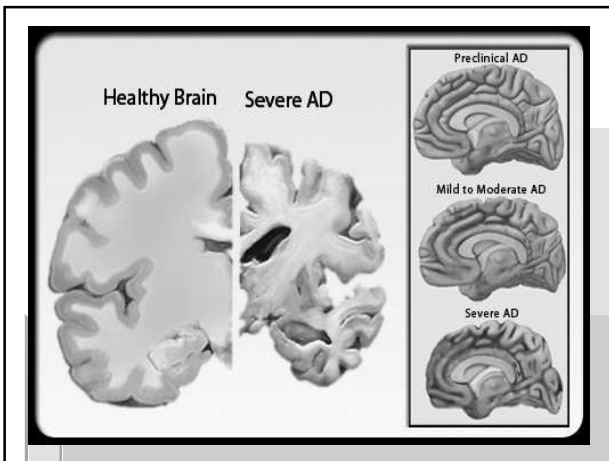
- Most common form of dementia
- Associated with plaques and tangles in the brain which interfere with normal functioning of neurotransmitters in the brain
- Duration can last as long as 20 years, but on average the duration is 8 years

Duplex, N. Recognizing pain in the Hospice patient with dementia. Retrieved from <http://www.healthcareupdate.com/content/2013/03/2013030201>

healthy brain

advanced alzheimer's

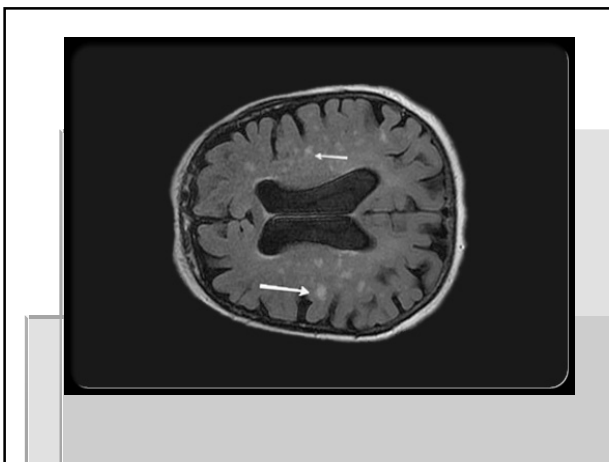




## Vascular Dementia

- Usually have history of hypertension or heart disease
- Usually occurs as a result of small strokes over time
- The onset of symptoms is usually abrupt and occur frequently after a stroke
- Course of disease is often sporadic
- Gait abnormalities common

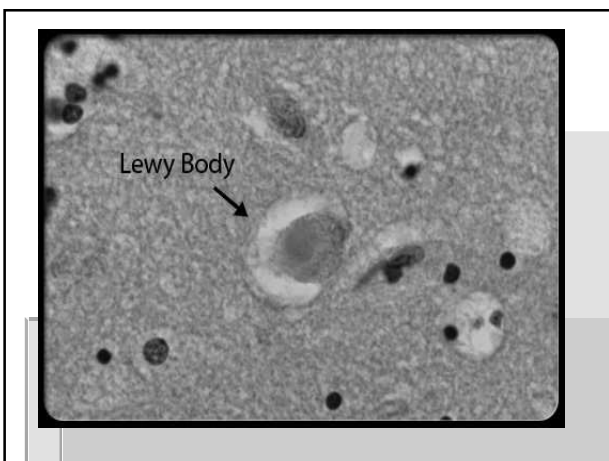
Depace, N. Recognizing pain in the Hospice patient with dementia. Retrieved from <http://thehealthcare.ecampus.com/printview.php?c=1018>



## Lewy-Body Dementia

- Accumulation of Lewy Bodies in parietal and frontal lobes of the brain which cause impaired cognitive function
- Degenerative Disease (average life expectancy 7yrs)
- Abnormal clumps of proteins found in the brains of these patients are found in patients with Alzheimer's and Vascular Dementia also, so patient's with this type of dementia will usually have symptoms associated with all of these diseases.
- Can have paranoia, hallucinations, agitation
- May have Parkinson's like symptoms
- Can have REM Sleep Disorder

Depace, N. Recognizing pain in the Hospice patient with dementia. Retrieved from <http://thehealthcare.ecampus.com/printview.php?c=1018>



## Characteristics Common to All Types of Dementia

- Memory impairment
- Loss of language
- Impaired motor skills
- Inability to recognize or identify objects
- Inability or difficulty planning and organizing

## Dementia is a terminal illness

## Dementia Admission Criteria for Hospice

- Unable to ambulate, dress or bathe without assistance
- Urinary or fecal incontinence, intermittent or constant
- Unable to speak more than six meaningful words per day
- Plus they must have had one of the following in the past year
  - Aspiration pneumonia
  - UTI or pyelonephritis
  - Sepsis
  - Multiple stage 3 or 4 decubitus ulcers
  - Fever that reoccurs after antibiotic therapy
  - Inability to maintain sufficient fluid and caloric intake with 10% weight loss during the previous 6 months or serum albumin levels less than 2.5g per dL

Schorrweiner, R., Han, B., Small, B., Martin, B., Tope, K., Halsey, W. (2003). Predictors of six-month survival among patients with dementia: an evaluation of hospice medicare guidelines. *Am J Hosp. Palliat. Care*

## Hospice Goals for Dementia Patients

- Promotes comfort and quality of life without use of life extending measures
- Focuses on close, collaborative working relationships between health care team, family, and patient
- Provides education that will allow the family to make informed decisions about the patient's healthcare needs
- Involvement of spiritual and religious counsel
- Assistance with the grieving process
- Knowledge that dementia is a terminal illness
- Offers diverse comfort measures to promote end of life care and quality of life

Smith, M. (2007). Hospice Approach to End of Life Dementia Care. University of Iowa College of Nursing Iowa Geriatric Education Center

## Barriers to Providing Hospice Services to Dementia Patients

- Terminal phase of dementia may be prolonged and difficult to predict
- People with end stage dementia lack the decision making skills to elect Hospice services independently
- Patient's did not make their wishes known prior to becoming incompetent
- The patient may not appear as if they are terminal
- Use of Medicare Part A days when in facilities
- Lack of education that dementia is a terminal illness
- Medicare Hospice eligibility requirements

Smith, M. (2007). Hospice Approach to End of Life Dementia Care. University of Iowa College of Nursing Iowa Geriatric Education Center

## Overcoming Barriers to End of Life Care for Dementia Patients

- Education is key (i.e. dementia is a terminal illness, advancing to final stages of disease, and community awareness)
- Promote and support enrollment of dementia patients into our palliative care program
- Caregiver support and use of the whole interdisciplinary team

## Dementia Patient is Enrolled in Hospice

Now What?

## Common Problems in End of Life Care of Dementia Patients

- Caregiver guilt & stress
- Problem behaviors
- Aspiration
- Skin breakdown
- Pain
- Communication barriers
- UTI's

## Caregiver Guilt and Stress

- Provide active listening and support
- Know community and agency resources and use them
- Offer respite care if appropriate
- Bereavement counseling
- Understand that caregiver may have conflicting feelings of relief and sadness which can lead to increased stress and guilt
- Educate the family and caregiver about the dying process. Knowledge is power!

## Behavior Problems Common to Dementia Patients

- Agitation
- Aggression
- Sexually inappropriate behavior
- Hallucinations
- Delusions
- Anxiety
- Depression
- Screaming
- Resistance to care

**Dementia Residents' Behaviors Should be Viewed as a Means of Communication Rather than Behaviors to be Discounted or Dismissed**

Alzheimer's Association

## Triggers of Agitation in Dementia

Ham, R. J., Sloane, P.D., Warsaw, G.A., Bernard, M. A., & Flaherty, E. (2007).

INTERNAL STRESSORS	EXTERNAL STRESSORS
▪ Delirium	▪ Unaccommodating physical environment
▪ Depression	▪ Unaccommodating social environment
▪ Mania	▪ Caregiver Burden
▪ Anxiety	▪ Unskilled Caregiver
▪ Psychosis	
▪ Difficulty with ADL's	
▪ Pain	

## Management of Agitation in Dementia

- Define target agitated behavior
- Address impact of agitation on patient's and other's safety
- Identify triggers (caregiver, environment, or patient related)
- Institute non-pharmacological interventions
- Institute pharmacologic interventions (after other interventions exhausted)
- Provide intermittent follow-up

## Non-Pharmacological Interventions for Agitation

- Music therapy
- Modify environment (cover mirrors or windows, adjust lighting)
- If behavior is not bothering or harming someone else and provides stimulation or positive affect than it is appropriate to allow it to continue
- Provide social interaction when possible
- Examine the patient's previous routines and life history and determine if behavior may be due to a break in these life long routines
- Look for other causes of agitation (infections, pain, discomfort, or unmet needs)
- Avoid restraints
- Behavioral modification-don't fight aggressive behavior or resistance to care

Hem, P. J., Stone, P. D., Warsaw, G. A., Bernard, M. A., & Fisherty, E. (2007). Alzheimer's disease and other dementias. Primary Care Geriatrics: A Case Based Approach, 5<sup>th</sup> Edition, p. 210-233

## Pharmacological Interventions for Agitation

- Hallucinations, delusions, agitation, sun-downing may be improved with anti-psychotics like Risperdal.
- If any signs of depression, may be beneficial to treat (SSRI's preferred in this population)
- Anxiety may respond to benzodiazepines

Marshall, M. Dementia, Delirium, Depression, and Anxiety at End of Life. Horizon Hospice

## Special Considerations for Lewy Body Dementia

- Avoid the use of Thorazine and Haldol in patients with Lewy Body Dementia as this can cause severe reactions to include: sedation, rigidity, postural instability, falls, increased confusion, and neuroleptic malignant syndrome, and a much higher increase in mortality. Atypical antipsychotics (Risperdol) can be used with caution, but can cause similar reactions
- Patients with this type of dementia do seem to respond better to the Cholinesterase Inhibitors than patients with other types of dementia
- Klonopin can be used for patients who are experiencing REM sleep disorder

Neel, D. & Walling, A. (2006). Dementia with Lewy Bodies: An Emerging Disease. Am Fam Physician. 73(7):1223-1229

## Aspiration and Feeding Difficulty

- Result of disease progression
- Education of the family is essential
- Teach good feeding practices and aspiration precautions
- Feeding tubes have not been found to prolong the life of dementia patients and in fact have been associated with more complications and discomfort
- Discuss "pleasure feeds" with the family and modification of patient diet

## Communication Barriers

- Use of prompts: physical and verbal
- Caregiver input
- Physiologic indicators
- Observation
- Identify hearing and vision impairments; ask about prior use of assistive devices
- Approach from the front, make eye contact, address the person by name, and speak in a calm voice
- Talk first; pause; touch second, reducing the person's sense of threat

Frazier-Rios, D. & Zembranski, C. (2007). Communication Difficulties: Assessment and Interventions in Hospitalized Older Adults with Dementia Issue Number D7.

## Communication Techniques

Frazier-Rios, D. & Zembranski, C. (2007)

- | Problems  | Interventions  |
|---|--|
| <ul style="list-style-type: none"> <li>▪ Can the patient understand a yes/no choice?</li> </ul>   | <ul style="list-style-type: none"> <li>▪ Simple, direct questions that require only a yes or no response.</li> </ul>   |
| <ul style="list-style-type: none"> <li>▪ Does the patient curse, use offensive or aggressive language, or exhibit aggressive or combative behaviors?</li> </ul> | <ul style="list-style-type: none"> <li>▪ Don't reprimand. Respond to the emotion not the words. Validate feelings. Assess for unmet needs, including those related to misperceptions, hunger, thirst, toileting needs, pain, etc.</li> </ul> |
| <ul style="list-style-type: none"> <li>▪ Does the patient avoid verbalization altogether or mutter in various tones?</li> </ul>                                 | <ul style="list-style-type: none"> <li>▪ Read nonverbal communication that may seem meaningless to others and anticipate needs.</li> </ul>   |

## Skin Breakdown

- Repositioning
- Alternating air mattresses
- Barrier creams
- Family education
- Supplements if able to swallow
- Wound consult if appropriate

## UTI

- Incontinence care
- Foley if indicated (avoid if possible)
- Cranberry supplements (no strong evidence to support this)
- Family education on disease process
- Antibiotics when indicated

## Pain in Dementia Patients

- Use of self-rated pain scales not effective
- Several recent studies have indicated that dementia patient's are suffering and the risk of untreated pain increases with the severity of dementia
- Patient's with dementia can still perceive pain, however they may experience the intensity and affective aspects to a lesser extent
- These patients may have difficulty interpreting the pain sensation and expressing it which could explain why atypical behavior responses to pain occur (frowning, agitation, anxiety, restlessness, aggressiveness, and withdrawal)

Scherfer et al. (2005) Recent developments in pain in dementia. *BMJ*, 330(26).

## Assessing Pain in Dementia Patients

- Ask the patient if they are in pain
- If the patient is unable to respond, but appears uncomfortable search for potential causes of pain/discomfort
- Observe the patient for behavior changes
- Use of Behavioral Pain Assessment Tools
- Surrogate reporting of pain
- Attempt analgesic trial

Hart, K., Coyne, P., Ray, T., Moranam, R., McCarthy, M., Mehta, S., Poulos-Kelly, J., Weil, L. (2008). Pain assessment in the nonverbal patient: position statement with clinical practice recommendations. *Pain Management Nursing*, 7(2) p. 44-52.

## Behaviors That Could Indicate Pain in Dementia Patients

Atypical Behaviors	Expected Behaviors
▪ Agitation	▪ Guarding
▪ Irritability	▪ Moaning
▪ Restlessness	▪ Rubbing the area
▪ Confusion	▪ Crying
▪ Combativeness	▪ Grimacing
▪ Changes in appetite	
▪ Routine changes	

## Surrogate Pain Reporting

- Caregiver is usually the first to notice the change in the patient
- Have often developed the ability to interpret non-verbal cues of discomfort
- May over or under estimate patient pain level
- Should be used in conjunction with patient observation and history of present illness and known pain disorders

## Pain Assessment Tools for Dementia Patients

- ADD: The Assessment of Discomfort in Dementia Protocol
- DS-DAR: Discomfort in Dementia of the Alzheimer's Type
- CNPI: Checklist of Nonverbal Pain Indicators
- CNVI: Checklist of Nonverbal Pain Indicators
- PAINAD Scale: Pain Assessment in Advanced Dementia
- FLACC-Face, Legs, Activity, Cry, Consolability
- BODIES Approach to Pain

## No BODIES in Pain

- **B**-What **Behaviors** did you see
- **O**-How **Often** did the behaviors occur
- **D**-What was the **Duration** of the behavior
- **I**-How **Intense** was the behavior
- **E**-How **Effective** was treatment, if given
- **S**-What made the behaviors **Start/Stop**

Stow, L., Rapp, M., & Kurkin, M. (2005) Pain management in Persons with Dementia. Geriatrics, 60(5)

Pain Assessment Tools

### FLACC SCALE

Categories	Scoring		
	0	1	2
FACE	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested.	Frequent to constant quivering chin, clenched jaw.
LEGS	Normal position or relaxed.	Uneasy, restless, tense.	Kicking, or legs drawn up.
ACTIVITY	Lying quietly, normal position moves easily.	Squirming, shifting back and forth, tense.	Arched, rigid or jerking.
CRY	No cry, (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints.
CONSOLABILITY	Content, relaxed.	Reassured by occasional touching hugging or being talked to, distractable	Difficulty to console or comfort

UCLA David Geffen School of Medicine - Department of Anesthesiology

### Pain Assessment in Advanced Dementia (PAINAD) Scale

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
<b>Total**</b>				

\*Five-item observational tool (see the description of each item below).

\*\*Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").

Warden V, Bullock AC, Volcoe L. Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. J Am Med Dr Assoc. 2003;4:9-15.

### PACSLAC (Pain Assessment Checklist for Seniors with Limited Ability to Communicate) (Fuchs-Lacelle & Hadjistavropoulos, 2004)

<b>Facial expressions</b> <ul style="list-style-type: none"> <li>▪ Grimacing</li> <li>▪ Change in eyes</li> <li>▪ Frowning</li> <li>▪ Opening mouth</li> <li>▪ Creasing forehead</li> <li>▪ Clenching Teeth</li> <li>▪ Wincing</li> </ul>	<b>Social/personality/Mood indicators</b> <ul style="list-style-type: none"> <li>▪ Physical or Verbal aggression</li> <li>▪ Not wanting to be touched</li> <li>▪ Throwing things</li> <li>▪ Increased confusion</li> <li>▪ Upset</li> <li>▪ Agitated</li> <li>▪ Cranky/irritable</li> </ul>
<b>Activity/body movements</b> <ul style="list-style-type: none"> <li>▪ Uncooperative/resistant to care</li> <li>▪ Guarding sore area</li> <li>▪ Fidgeting</li> <li>▪ Restless</li> <li>▪ Refusing medications</li> <li>▪ Stiff/rigid</li> </ul>	<b>Physiological indicators/Eating/Sleep/Vocal Behaviors</b> <ul style="list-style-type: none"> <li>▪ Pale face</li> <li>▪ Teary eyed</li> <li>▪ Sweating</li> <li>▪ Changes in appetite</li> <li>▪ Screaming/yelling</li> <li>▪ Moaning and groaning</li> </ul>

## Search for Causes of Pain

### Acute Causes of Pain

- Constipation
- Inflammation
- Infection
- Fractures
- Pressure ulcers
- Painful procedures
- Activities of daily living

### Chronic Causes of Pain

- Arthritis (common)
- Neuralgias
- Neuropathy
- Polymyalgia Rheumatica
- Phantom limb pain
- Spinal stenosis
- Old fractures
- Diagnoses of cancer

## Non-Pharmacological Interventions for Pain Relief

- Repositioning
- Toileting
- Assessing for hunger or thirst
- Managing environmental stimuli (soothing music, adequate lighting,
- Ensure adequate fit of personal items (dentures, clothing, shoes, etc.)
- Massage therapy

## Analgesic Trials

### Step-Method

- Mild Pain: non-narcotic analgesics (Tylenol 500-1000mg Q6hrs, NSAID Trial with observation for GI stress, Lidocaine Patches)
- Moderate Pain: may use Tramadol, Codeine, Oxycodone as tolerated
- Severe Pain: Morphine, Fentanyl, Dilaudid

Powers, Richard. Management of the Hospice Patient with Dementia

## Analgesic Trials

- Neuropathic Pain: Neurontin, Tri-cyclic Anti-depressants
- Depression- can intensify pain. SSRI's are drug of choice, however Tri-cyclic Anti-Depressants can also be used

Powers, Richard. Management of the Hospice Patient with Dementia

## Analgesic Trials

- Should see improvement in behaviors fairly quickly if pain is the issue
- Dose reduction of 25-50% when dosing opioids (start low and go slow)
- Avoid the use of Darvocet in this population due to increased confusion and risk of falls
- Re-evaluate for improvement or effectiveness frequently
- Monitor for unwanted side effects (lethargy, nausea, constipation, risk of falls)
- Weigh benefit vs. risk

Hart, K., Coyne, P., Kelly, T., Manosson, B., McCaffery, M., Merkel, S., Pickett-Kelly, J., Weil, L. (2006). Pain assessment in the nonverbal patient: position statement with clinical practice recommendations. Pain Management Nursing, 17(2), 44-62.

## Is There a Tool Available to Rate Suffering in End of Life Dementia Patients?

## Mini-Suffering State Examination

- Reliable and valid clinical tool, recommended for evaluating the severity of the patient's condition and the level of suffering of end stage dementia patients (Aminoff, et. Al., 2004), (Aminoff & Adunsky, 2006)
- Takes into account "the whole picture" in that it focuses on potential problems in this population and includes the opinions of caregivers and medical staff



### Mini-Suffering State Examination (MSSE)

(Aminoff BZ, Gerontologie und Geriatrie 1999; Aminoff BZ, Purits E, Noy S, Adunsky A. Measuring the suffering of end-stage dementia: reliability and validity of the Mini-Suffering State Examination. Arch Gerontol Geriatr 2004;38(2):123-130.)

Suffering items Yes (1)/no (0)

1. Not calm
2. Screams
3. Pain
4. Decubitus ulcers
5. Malnutrition
6. Eating disorders
7. Invasive action
8. Unstable medical condition
9. Suffering according to medical opinion
10. Suffering according to family opinion

MSSE score, total  
MSSE score interpretation:

Low level of suffering 0-3  
Intermediate level of suffering 4-6  
High level of suffering 7-10

## Key Points to Remember

## Key Points

- Dementia is a terminal illness
- Family education is important
- We should assume that dementia patients with conditions that would cause pain in non-demented patients, would cause the same pain in this population
- Communication barriers are no excuse for poor symptom management
- When providing symptom management for these patients "start low and go slow"
- These patients can not change their behaviors, therefore the burden lies on us as healthcare professionals to change our behaviors to care for this special population
- Remember the interdisciplinary team when providing end of life care for dementia patients and use them
- Don't forget about the caregiver

## Questions????

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