

# 1.17 Dementia

## Key Points

1. Dementia causes suffering.  
Both patients and their families suffer with physical, spiritual, emotional, and social distress.
2. Dementia requires defining Goals of Care.  
An important role for physicians is to help patients and families define Goals of Care and develop plans for the future.
3. Key markers of advanced dementia indicate referral for hospice care.  
Key markers include inability to walk independently, fewer than six intelligible words, and decline in oral intake.
4. Palliative care is an appropriate treatment philosophy for most patients with dementia.  
A subset of patients with advanced dementia will be eligible to use the Medicare hospice benefit.
5. Housestaff often encounter patients in crisis indicative of complications of late dementia.  
Frequently the crisis indicates the need to change location of care (i.e., home to nursing home).
6. Care of dementia patients should include advance care planning.  
Advance care planning can help patient and family regain a sense of control and reduce suffering and conflict during times of crisis.

# Dementia



## The Palliative Response

### Dementia Causes Suffering

- Physical
- Emotional
- Social
- Spiritual

*Both the person afflicted with dementia and the person's family will experience suffering in any or all of these domains*

### Dementia and Palliative Care

- Most patients and families living with dementia would benefit from the palliative-care approach to the assessment and treatment of their suffering
- Suffering has multiple domains and is best addressed in an interdisciplinary process

### Dementia and Hospice Care

A select subset of all patients with dementia will qualify for services through the Medicare hospice benefit.

### The Physician's Role

- Evaluation and diagnosis of dementia
- Search for reversible causes (rare)
- Management of current medical problems
- Sensitive revelation of the diagnosis and prognosis
- Assist in defining Goals of Care

### The Physician's Role Medical Management

- Management of acute, often recurrent and infectious illnesses  
*Pneumonia*  
*UTI*
- Management of co-morbid illness  
*Treatment may be more difficult, especially in the advanced stages of dementia*

## The Physician's Role

### Late-Stage Dementia

- Evaluation of key markers of late-stage dementia
  - Inability to walk independently*
  - Fewer than six intelligible words*
  - Decline in oral intake and nutritional status*
  - Frequent ER visits and hospital admission*
- Management of late-stage dementia
- Transition to hospice care

## Dementia: Physical Suffering

### Pain

- Pain from complications of dementia is often undertreated due to difficulty with self-reporting

### Infections

- Pneumonia
  - Aspirations and atelectasis*
- UTI
  - Diapers and indwelling catheters*

## Dementia: Physical Suffering

### Decubitus ulcers

- Incontinence
- Immobility
- Restraints
- Poor hygiene
- Decreasing nutritional status

## Dementia: Physical Suffering

### Asthenia

- Falls
- Bed or chair confinement
- Medical interventions and iatrogenic injury
  - Nasogastric tubes and PEG tubes*
  - Foley catheters*
  - IVs*
  - Restraints to protect other interventions or to prevent attempts to get up*

## Dementia: Emotional Suffering

### Depression

- May benefit from treatment with SSRI

### Cognitive loss

- May benefit from treatment with medications like donepezil (Aricept) in early-to-moderate stages
- May cause unacceptable side effects without benefit

## Dementia: Emotional Suffering

### Delirium

- Wandering and sun-downing
- Often worsened by even a minor illness
- Disturbance of sleep-wake cycle disrupts home
- Usually less intense in familiar environments

## **Dementia: Caregiver Suffering**

- Depression  
*Referral for treatment*
- Fatigue  
*Respite*
- Anger  
*Support groups*
- Guilt  
*Spiritual counsel/ support groups*

## **Dementia: Social Suffering**

- Loss of independence
- Family struggles with role reversal
- Declining health or death of spouse complicates care
- Loss of financial resources
- Need to change location of care

## **Dementia: Social Suffering**

Need to change location  
of care

- Living at home alone
- Assistance in home
- Living with others
- Assisted-living facility (ALF)
- Nursing home

## **Dementia: Spiritual Suffering**

- Guilt
- Anger
- Inability to maintain relationship with faith community
- Feelings of abandonment

## **Advance Care Planning in Early Dementia**

Patient can help make decisions

- Surrogates for decision-making
- Preferred locations of care
- Feeding tubes
- Resuscitation and other aggressive interventions

## **Advance Care Planning in Advanced Dementia**

Family and caregivers  
discuss decisions

- Transitions to other venues of care
- Response to complications and progression of illness
- Feeding tubes
- Resuscitation attempts

## Prognosis

Prediction by fast scoring

- Development of incontinence  
*Usually will require transfer from ALF to nursing home*
- FAST Score of 6 or 7  
*May predict a less than six-month survival*  
*Qualifies patient for referral to hospice*

## Prognosis

Key indicators for limited prognosis

- Loss of ability to ambulate independently
- Fewer than six intelligible words
- Declining oral intake

## Prognosis

Key indicators for limited prognosis

- Markers of advanced dementia predict  
*Frequent ER visits*  
*Frequent hospital admissions*

## Prognosis

Key indicators for limited prognosis

- Markers should prompt:  
*Discussion with surrogates of limited prognosis*  
*Review or development of Advance care plan*  
*Consideration of hospice referral*

# Dementia

## Selected Readings

### Life Expectancy

Wolfson, C., D. B. Dolfson, M. Asgharian, C. E. L'Lan, T. Ostbye, D. K. Bockwood, and D. B. Hogan. "A Reevaluation of the Duration of Survival after the Onset of Dementia." *New England Journal of Medicine* 344 (2002): 1111–1116.

### Advance Care Planning

Marin, D. B., E. Rudin, B. Fox, J. Neugroschl, A. Brickman, J. Northrop, E. Fine, G. Zaklad, R. S. Morrison, and D. E. Meier. "Feasibility of a Health-Care Proxy Counseling Program for Patients with Alzheimer's Disease." *Journal of Palliative Medicine* 2 (1999): 323–329.

### Health Care for Advanced Dementia

Ahronheim, J. C., R. S. Morrison, S. A. Baskin, J. Morris, and D. E. Meier. "Treatment of the Dying in the Acute Care Hospital: Advanced Dementia and Metastatic Cancer." *Archives of Internal Medicine* 156 (1996): 2094–2097.

Luchine, D. J. and P. Hanrahan. "What Is Appropriate Health Care of End-stage Dementia?" *Journal of the American Geriatrics Society* 41 (1993): 25–30.

### Tube Feeding

Meier, D. E., J. C. Alronheim, J. Morris, S. Baskin-Lyons, and R. S. Morrison. "High Short-term Mortality in Hospitalized Patients with Advanced Dementia: Lack of Benefit of Tube Feeding." *Archives of Internal Medicine* 161 (2002): 594–599.

### Communication

Thompson, P. M. "Communicating with Dementia Patients on Hospice." *American Journal of Hospice and Palliative Care* 19 (2002): 263–266.

### Nursing-Home Placement

Yaffe, K., P. Fox, R. Newcomer, L. Sands, K. Lindquist, K. Dane, and K. E. Covinsky. "Patient and Caregiver Characteristics and Nursing Home Placement in Patients with Dementia." *Journal of the American Medical Association* 287 (2002): 2090–2097.