

Palliative Care & Dementia

Karen B. Hirschman, PhD MSW
Research Assistant Professor
School of Nursing, University of Pennsylvania
NewCourtland Center for Transitions and Health

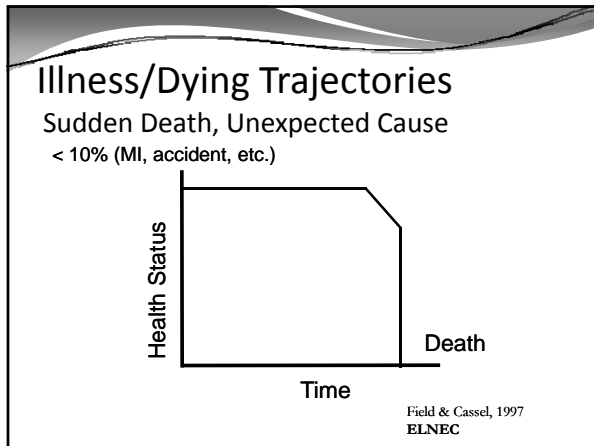


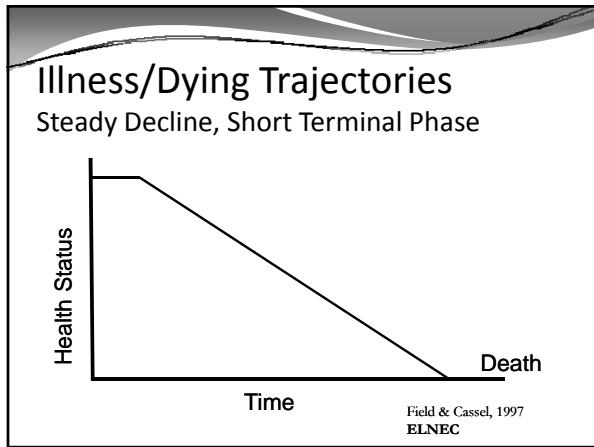
2010 Penn Future of Hospice & Palliative Care Conference
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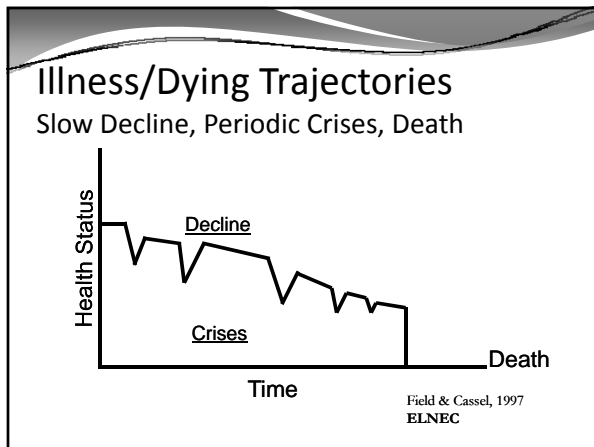
Objectives

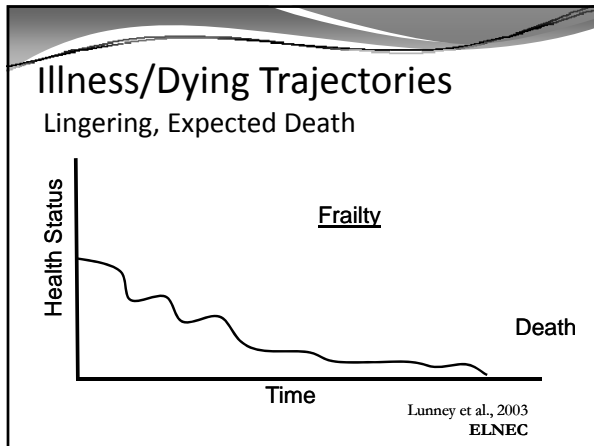
- To define and describe palliative care
- To define and describe the stages of dementia (mild to terminal)
- To apply hospice guidelines for dementia
- To assess pain and symptoms of discomfort in patients with dementia

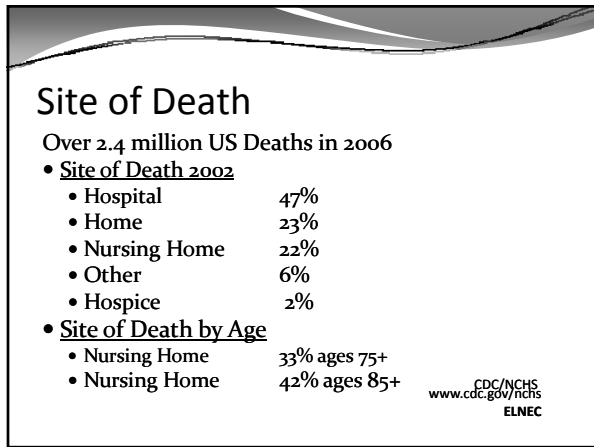
Historical Context of End-of-Life Care

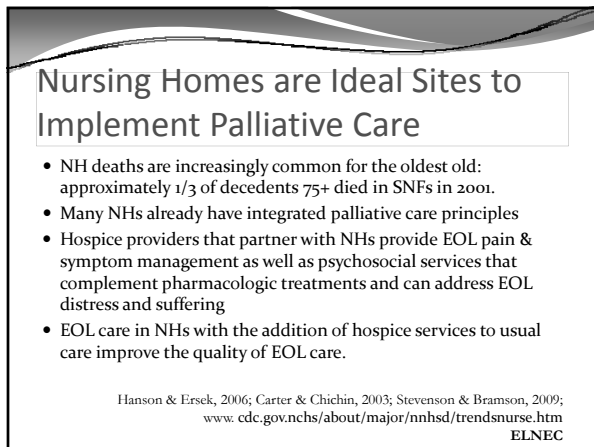












Hospice and Palliative Care

- **HOSPICE**
 - Most intense form of palliative care
 - Less than 6 months to live
 - Agrees to enroll in hospice program
 - Chooses not to receive aggressive curative care
- **PALLIATIVE CARE**
 - Ideally begins at the time of diagnosis
 - Can be used to complement aggressive treatments

NCP, 2009
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Emergence of Palliative Care

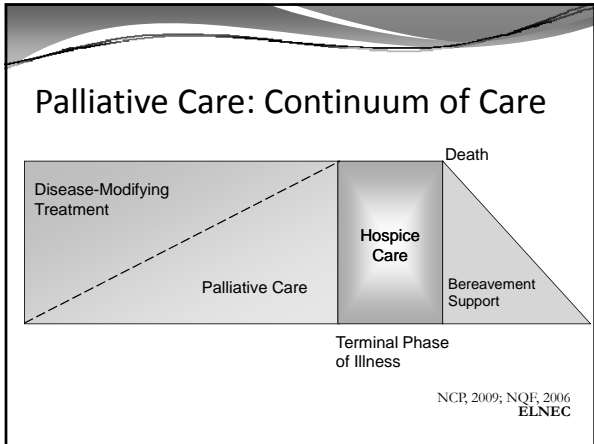
- Movement began in 1980s, gaining momentum throughout the 1990s
- Goal: to move hospice care “upstream”
- Hospices expanded services
- Academic palliative care programs were instituted

NCP, 2009; www.capc.org
ELNEC

Definition of Palliative Care

- Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.

NCP, 2009; NQE, 2006
ELNEC



Room for Improvement

- Despite progress, there is room for improvement in EOL care for older adults
 - Especially those with dementia

Do they look like they have dementia?

“Normal” cognitive changes with age

- Cognitive changes do occur but are not severe enough to interfere with everyday function
- Intellectual response time slows with aging
 - Non-demented older adults take longer than young adults to complete memory tasks and solve problems, but accuracy is unaffected

The aging brain

- Our brains are like our bodies
 - We can change our brains
- “Dementia” is a catch all term for at least 6 months of progressive losses in brain function that interfere with a person’s ability to do their usual and everyday tasks
- The most common disease that causes dementia is Alzheimer’s Disease

Causes of cognitive impairment

- Things in the brain
 - Developmental disorders
 - Neurodegenerative diseases: dementia
 - Affective impairment: depression, anxiety, delusions
- Things outside the brain
 - Intoxication: liquor, drugs, or medications
 - Medical illnesses that injure brain
 - Head injury

Cognition: It's not just memory

- **Definition:** the mental activities of knowing, thinking, learning and judging
- **Divided into domains or areas:**
 - **Attention** - ability to stay focused on a task
 - **Memory** - long term & short term
 - **Language** - speaking & comprehending others
 - **Praxis** - making sense of what you see & do
 - **Executive Function** - planning & organizing

Case #1

- 88 year-old nursing home resident with Alzheimer's Dementia who has lived there for the past 5 years since his wife passed away. He requires cueing for dressing, bathing, and toileting, however eats independently when food is set up in front of her. He knows his name, but does not know the date or his residence and only sometimes he recognizes his children.
- What stage of dementia does he have?

Stages of Dementia

MILD	
Function	-independent of all ADLS, may need assistance with complex task
Cognition	-difficulty learning new information -memory loss interferes with everyday functions -mild word finding difficulty but maintain social conversation -mild judgment impairment
Behavior	-mild personality changes
MMSE	≥19

MMSE=Mini Mental State Examination (range: 0-30 n cognitive test)
Cotter, VT, et al. Dementia. Geriatric Secrets 3rd Edition. Hanley & Belfus, 2004, 53. Adapted from Cotter, VT. Forgetfulness. Goodby, MJ. Nurse Practitioner Secrets, Philadelphia, Hanley & Belfus, 2002, 64-70.

Stages of Dementia

MODERATE	
Function	-independent of all ADLS, may need reminders or minimal assistance -assistance or complete dependence with IADLs
Cognition	-substantial memory loss, disoriented in time and often to place -conversation disorganized, rambling -impaired judgment
Behavior	-may have psychotic behavior, wandering, agitated verbal or physical symptoms -sleep disturbance -appears well enough to be taken to functions outside of home environment
MMSE	12-19

Stages of Dementia

SEVERE	
Function	-dependent of all IADL -dependent of ADLs (incontinent, may need assist eating)
Cognition	-oriented to person only -only fragments of memory retained -severe language impairment -inconsistent recognition of familiar people -vary short attention span
Behavior	-emotional lability -restlessness -inability to focus on tasks -appears ill to be taken to functions outside the home
MMSE	0-11

Advanced Stages of Dementia

PROFOUND	
Function	-dependent of all IADL -dependent of ADLs (loss of ambulation, feeds with assistance)
Cognition	-speaks <6 words -consistent difficulty in recognizing familiar people
Behavior	-repetitive vocalizations, calling out
MMSE	<11

Advanced Stages of Dementia

TERMINAL	
Function	-inability to walk or sit up without assistance -inability to smile or hold head up ≥10% body weight loss, pressure ulcers >stage 2, UTIs, aspirations pneumonias
Cognition	-few words spoken
Behavior	-passive
MMSE	Not testable

Mortality (2000-2006)

Deaths from:	% (direction)
Alzheimer's disease	46.1% (increase)
Heart disease	11.1% (decrease)
Breast Cancer	2.6% (decrease)
Prostate Cancer	8.7% (decrease)
Stroke	18.2% (decrease)
HIV/AIDS	16.3% (decrease)

2010 Alzheimer's Disease Facts and Figures, Fact Sheet, Alzheimer's Association
http://www.alz.org/national/documents/topicsheet_2010_facts_figures.pdf

Issues in late stage dementia

- Making plans for transitions in care
- Interpreting cognition
- Maintaining dignity and quality of life
- Symptom management
- Coming to terms with grief and loss

Case #2

- 84 year old female with PMH of dementia, HTN, and urinary incontinence who lives in assisted living.
- She has round the clock paid caregiver support through the ALF and a daughter who visits regularly.
- ALF staff found the patient more confused than usual and sent her to the ER for evaluation.
- She was admitted to the hospital for new onset confusion.

Case #2: Previous 6 months

- Functional decline noted by both daughter and caregivers
- Less cooperative with care
- Less talkative and less appropriate with answers
- Needing more assistance with all basic Activities of Daily Living (ADLs)
- He has lost 20 pounds over the past 6 months

Case #2: Hospital Stay

- Found to have Acute Renal Failure thought to be pre-renal due to dehydration and poor intake→resolves with intravenous fluids.
- As well as urinary tract infection-->resolves with antibiotics.
- During her hospitalization he develops a stage 3 pressure ulcer.
- Patient no longer able to get out of bed and requires maximum assistance with all ADLs. He is also not cooperating with physical therapy.

Recent study findings

- **Hospital Characteristics Associated with Feeding Tube Placement in Nursing Home Residents with Advanced Cognitive Impairment**
 - Teno et al. JAMA. February 10, 2010; 303(6):544-50
- **The Clinical Course of Advanced Dementia**
 - Mitchell et al. NEJM. October 15, 2009; 361(16):1529-38

Hospital Characteristics & Feeding Tube Placement (Teno et al 2010)

- 2797 Acute care hospitals
 - >280,000 admissions among 163,022 NH residents with advanced cognitive impairment
- Identify characteristics associated with higher rates of feeding tube insertion in NH residents with advanced CI
- For-Profit, larger hospital size, and greater ICU use associated with increased rates of feeding tube insertion
 - Only 5.8% of hospitalized NH residents with advanced CI had an order to forgo artificial hydration & nutrition

Teno, et al. Hospital Characteristics Associated with feeding Tube Placement in Nursing Home Residents with Advanced Dementia. JAMA. 2010. 303(6):2734-2740.

Clinical Course of Advanced Dementia

- NH residents over 18 months
- Probability of pneumonia was 41.1%; a febrile episode, 52.6%; and an eating problem, 85.8%
- 6-month mortality rate for residents who had pneumonia was 46.7%; a febrile episode, 44.5%; and an eating problem, 38.6%
- Distressing symptoms
 - dyspnea (46.0%)
 - pain (39.1%)

Mitchell S et al. The Clinical Course of Advanced Dementia. NEJM. 2009; 361:1529-38

Clinical Course of Advanced Dementia (cont.)

- In the last 3 months of life,
 - 40.7% of residents underwent at least one burdensome intervention (hospitalization, emergency room visit, parenteral therapy, or tube feeding)
- Residents whose proxies had an understanding of the poor prognosis and clinical complications expected in advanced dementia were much less likely to have burdensome interventions in the last 3 months of life than were residents whose proxies did not have this understanding.

Mitchell S et al. The Clinical Course of Advanced Dementia. NEJM 2009;361:1529-38

Case #2 - Family Discussion

- Family does not wish to pursue aggressive work-up.
- Due to the progressive decline over the past 6 months the team discusses options, including hospice.
- Palliative Care consult.
- Healthcare-proxy, his daughter, feels that hospice is the most appropriate and would support her father's previously expressed wishes.

Hx of the Dementia Guidelines

- Guidelines NOT criteria for admission to hospice!
- Consensus NOT evidence-based!
- Luchins study was completed around the same time as the initial guidelines were published in the late 1990s

Evidence Based Medicine for Dementia Prognosis...What there is of it!

- 1997 Luchins' Study published in JAGS around the same time as development of Dementia Criteria for hospice admission, used FAST
- 2004 Mitchell Study published in JAMA

Functional Assessment Staging

FAST Stages

1. No difficulties
2. Subjective forgetfulness
3. Decreased job functioning and organizational capacity
4. Difficulty with complex tasks, instrumental ADLs
5. Requires supervision with ADLs
6. Impaired ADLs, with incontinence
7. *A. Ability to speak limited to six words*
B. Ability to speak limited to single word
C. Loss of ambulation
D. Inability to sit
E. Inability to smile
F. Inability to hold head up

Fast Fact and Concept #150: Prognostication in Dementia. Sing Tsai MD and Robert Arnold MD
<http://www.aahpm.org/cgi-bin/wkcg/view?status=A%20&search=185&id=659&offset=225&limit=25>

Criteria for Enrolling Dementia Patients In Hospice (Luchins et al 1997)

- Studied the relationship of FAST to survival
 - 47 patients with advanced dementia and 1 or more dementia related co-morbidity
- Median survival time all patients = 6.9 months
 - 37% survived longer than 6 months
- For those who could be assigned a FAST stage (n=17):
 - **Score 7C or greater: mean survival 3.2 months**
 - **Score less than 7C: mean survival 18 months**

Dementia Prognosis Study

(Mitchell et al. 2004)

Mortality Risk Index (MRI)

- Modified specific MDS (minimum data set) used in long-term care facilities
- Developed & modified using sample all NH residents (N>10,000)
 - Advanced dementia sample size: n=1922
- More consistent and effective with prediction of prognosis of <6 months

Mortality Risk Index Score for Stratification of Residents Into Levels of Risk for 6-Month Mortality

Score Sheet to Estimate 6-Month Prognosis in Nursing Home Residents With Advanced Dementia

Risk Factor From Minimum Data Set	Points	Score
Activities of Daily Living Scale = 20*	1.9	—
Male Sex	1.9	—
Cancer	1.7	—
Congestive Heart Failure	1.6	—
Oxygen Therapy Needed in Prior 14 Days	1.6	—
Shortness of Breath	1.5	—
<25% of Food Eaten at Most Meals	1.5	—
Unstable Medical Condition	1.5	—
Bowel Incontinence	1.5	—
Bedfast	1.5	—
Age ≥83†	1.4	—
Not Awake Most of the Day	1.4	—

Total Risk Score, Rounded to Nearest Integer
Possible Range, 0-19

*The Activities of Daily Living Scale is obtained by summing the resident's self-performance ratings on the Minimum Data Set for the following 7 functional activities: bed mobility, dressing, toileting, transfer, eating, grooming, and locomotion. In the Minimum Data Set, functional ability is rated on 5-point scale for each activity: 0, independent; 1, supervision; 2, limited assistance; 3, extensive assistance; and 4, total dependence. A total score of 20 represents complete functional dependence.

Mitchell, S. L. et al. JAMA 2004;291:2734-2740.

If Total Risk Score is...	Risk Estimate of Death Within 6 Months, %
0	8.9
1 or 2	10.8
3, 4, or 5	23.2
6, 7, or 8	40.4
9, 10, or 11	57.0
≥12	70.0

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Current Hospice Dementia Guidelines

NHPCO guidelines state severity of dementia (FAST >7a) is appropriate for hospice enrollment, based on an expected six month or less prognosis, if the patient also exhibits one or more specific dementia related co-morbidities **within the past 6 months:**

- Aspiration pneumonia
- Pyelonephritis
- Septicemia
- Multiple, progressive stage 3-4 decubitus ulcers
- Fever after antibiotics
- Unable to maintain fluid/caloric intake to sustain life
- If feeding tube in place, weight loss>10% in 6 months or serum albumin <.5gm/dl are helpful indicators

Helpful Documentation

- Downward Trends over the past 6 months-1 year:
 - Weight
 - Albumin levels
 - Intake – how long it takes to feed each meal, modification of diet texture
- Skin integrity
- Changes in function, behavior and cognition

Case #2: Back to Our Patient

- She is enrolled in home hospice at the ALF.
- She receives home visits from RN 1-2x/week and agency caregiver for 8 hours/week from hospice.

**Does he look like
he is in pain?**



Pain in Older Adults

- 25 – 56% community-dwelling elders
- 45 – 85% nursing home residents
- 30% cancer patients receiving treatment
- Up to 80% of older persons with advanced cancer
- 20% of hospitalized patients in their last days of life

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Assessment in Older Adults

With & Without Cognitive Impairment

- **What type of questions would you ask?**
 - How limited in basic activities?
 - How is their sleep?
 - How is their appetite?
 - Can they rate the pain?
 - How is their mood?
 - How are their interpersonal interactions?
 - Any change in mental status?

Pain Assessment in Nonverbal Older Adults

- Advanced dementia
- Progressive neurological disease
- Post CVA
- Imminently dying
- Developmentally disabled
- Delirium



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Case #3

- 95 year-old male with end-stage dementia. He has been on tramadol twice daily with acetaminophen as needed for history of osteoarthritis-type pain and is now no longer taking much by mouth.
- How do you assess him for pain or discomfort?

Differences in the Pain Experience of Older Adults with Dementia

- Tolerance to *acute* pain *possibly* increases but pain threshold does not appear to change
- Dementia may blunt response to acute pain
- Cognitive impairment *may* decrease the perceived analgesic effectiveness
- Pain can negatively affect cognitive function

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Adequate Pain Assessment

- Requires repeat comprehensive assessments
- Check at rest and with movement
- Older adults under-report pain → "normal aging"

Can Older Adults with CI Give Reliable Pain Reports?

- Various studies
 - CI residents slightly underreport pain, but their reports are valid
 - 83% of residents with mild to moderate CI could reliably complete at least one pain scale
 - 73% of post-op patients with moderate CI were able to complete a 4-point verbal descriptor scale

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CI & Pain Management

- Pain is documented less frequently for CI elders, despite having similar numbers of painful diagnoses as less impaired elders
- Less analgesic is prescribed and administered for CI elders, despite similar numbers of painful diagnoses
- Among NH residents, those who are CI are at increased risk for undertreatment of pain compared with cognitively intact residents

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Behavioral/Observational Cues

Obvious:

- Grimacing or wincing
- Bracing
- Guarding
- Rubbing

Less Obvious:

- Changes in activity level
- Sleeplessness, restlessness
- Resistance to movement
- Withdrawal/apathy
- Increased agitation, anger, etc.
- Decreased appetite
- Vocalizations



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Possible Causes of Physical Pain in Individual's with Dementia

- Constipation or diarrhea
- Lodged food particles
- Contractures
- Pressure ulcers
- UTI
- Pre-existing conditions, e.g. arthritis



Shega, et al., 2007
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Pain Behavior Assessment Tools

- Checklist for Nonverbal Pain Indicators (CNPI) (Feldt, 2000)
- NOPAIN (Snow et al., 2004)
- PAIN-AD (Warden et al., 2003)
 - Many other scales out there for pain but limited for nonverbal pain

Available at: <http://prc.coh.org/elderly.asp>

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Nursing Resources in Geriatric Pain

- GeriatricPain.org is a web resource that supports recommendations for good pain assessment and management in older adults to assist nurses with responsibility for pain care in the nursing home.
- ConsultGerRN.org is the evidence-based geriatric clinical nursing website that is endorsed by the following organizations: National Gerontological Nursing Association (NGNA), American Association for Long Term Care Nursing (AALTCN), The National Association Directors of Nursing Administration in Long Term Care (NADONA), and others.

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Case #3 Back to Our Patient (cont.)

- Restless at rest (moving his legs)
- Nonverbal, barely opening his eyes
- Grimacing with personal care

Take Home

- Dementia is a leading cause of death in the United States
- Dementia is under recognized as a terminal illness
- Importance of pain assessment in those with dementia

Acknowledgements

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