Friday, July 30, 2021

Navian HAWAII

care for every life journey

FORMERLY HOSPICE HAWAII

# The Benefits of Hospice & Palliative Care for Persons with Advanced Dementia

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July 30, 2021

40+ Years of Hope

# Sponsored by





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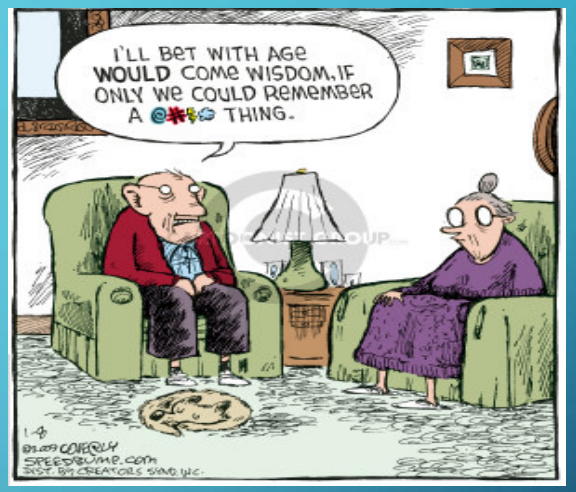
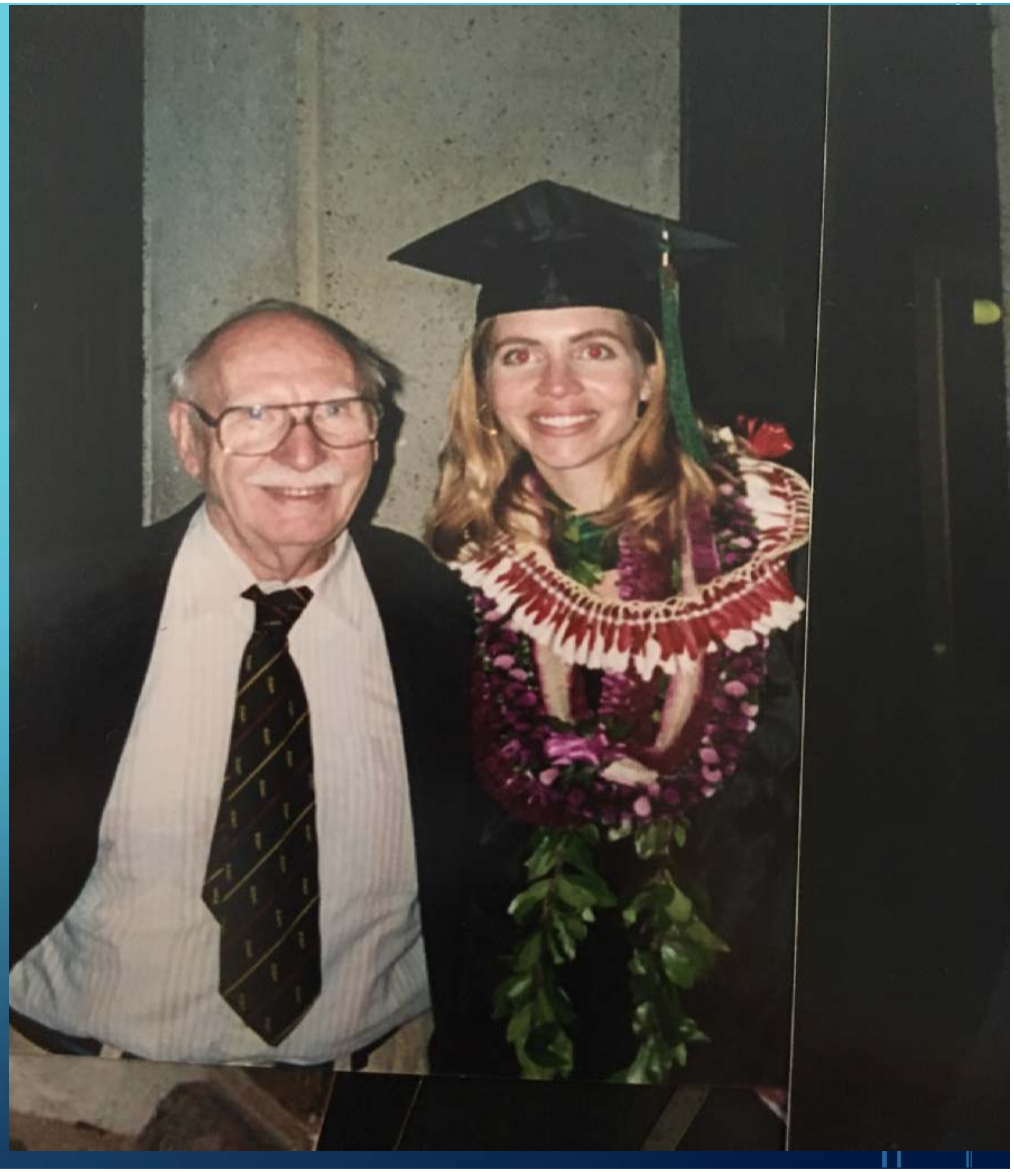
# OBJECTIVES




- Hospice & Palliative Care
- Review criteria for hospice admission
- Common complications in end-stage dementia
- "Burdensome" interventions that frequently occur near end of life
- Benefits of hospice/palliative care for persons with advanced dementia and their caregivers

# A PERSONAL JOURNEY



# SCOPE OF THE PROBLEM IN THE USA

- 2020 - 5.8 million Americans were living with Alzheimer's disease
- 2060 - projected to have 14 million effected by disease
- The 6th leading cause of death among US adults
- The 5th leading cause of death among adults > 65 years

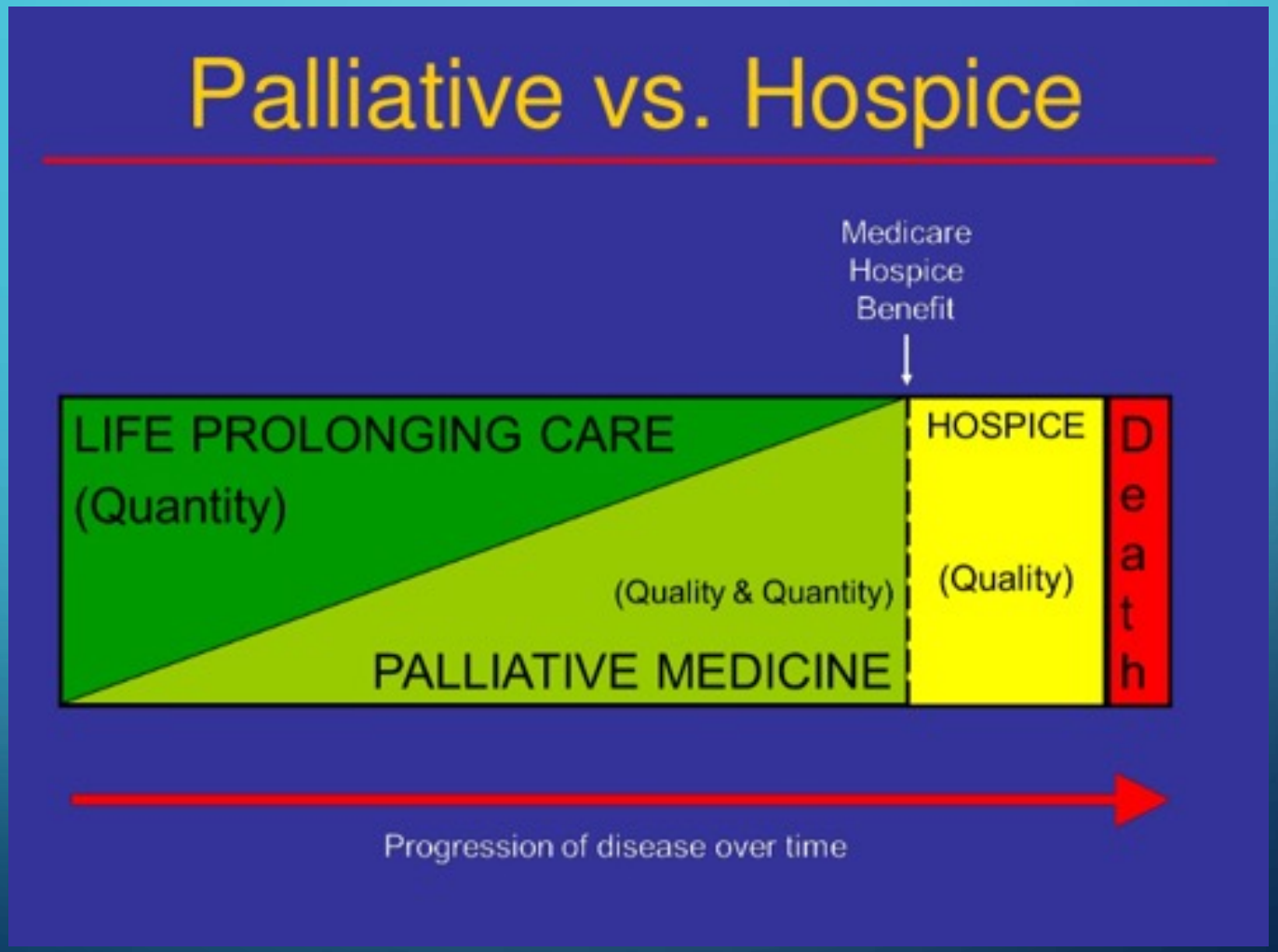
# PALLIATIVE CARE:

- Specialized care for people living with a serious illness
- Goal:
  - improve quality of life for both the patient and the family/caregiver.
- Focuses on:
  - Symptom management
  - Stresses of the illness
  - Understanding disease progression & choices for medical treatment
- Based on the needs of the patient, not on the patient's prognosis.
- Care team: doctors, nurses, social workers, spiritual support

# HOSPICE CARE:

- Specialized care for people in last 6 months or life
- Focuses on:
  - Aggressive symptom management
  - Holistic Support of quality of life
  - Supporting the caregiver
  - Assistance with ADL's such as bathing
  - Grief and bereavement counseling for the patient and family
- Can occur at home, foster home or in nursing facility
- Care Team: nurses, social workers, doctors, nurse assistants, spiritual advisors and volunteers

# Palliative vs. Hospice



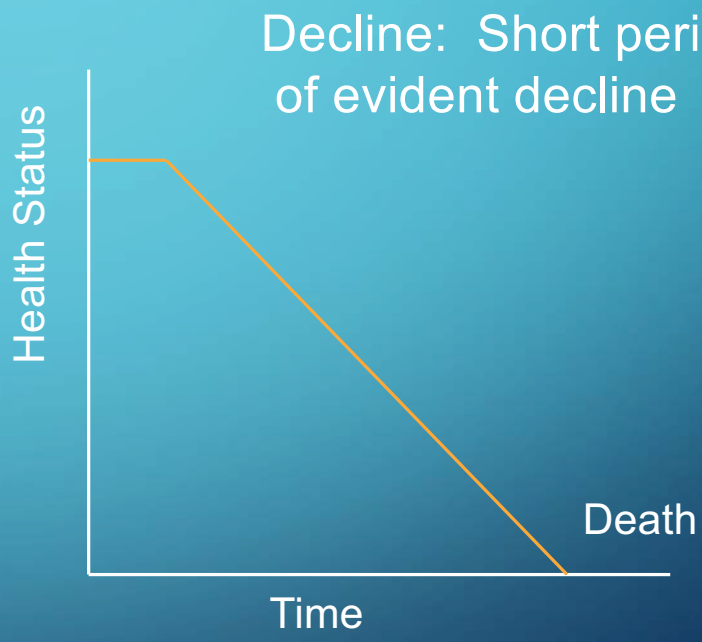
# MEDIAN SURVIVAL

- Ranges from 3 -12 years
- Vascular and Lewy body dementia have shorter prognosis
- People diagnosed at a later age have shorter survival

# THE DIFFICULTY IN PROGNOSTICATION

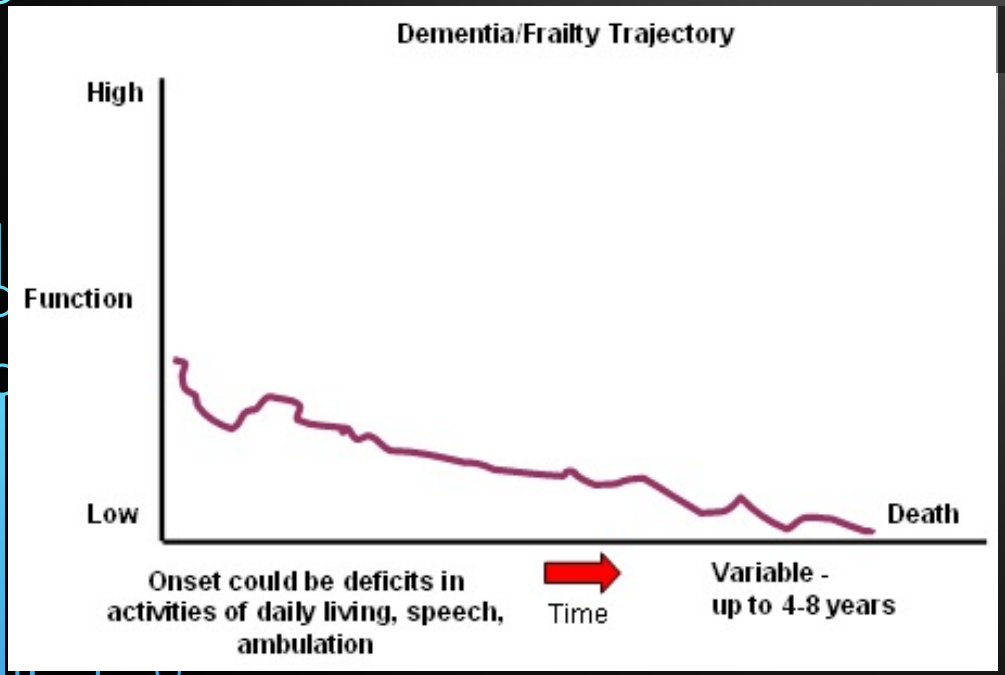
**Figure 10: % of Hospice Decedents by Principal Diagnosis for 2017 & 2018**

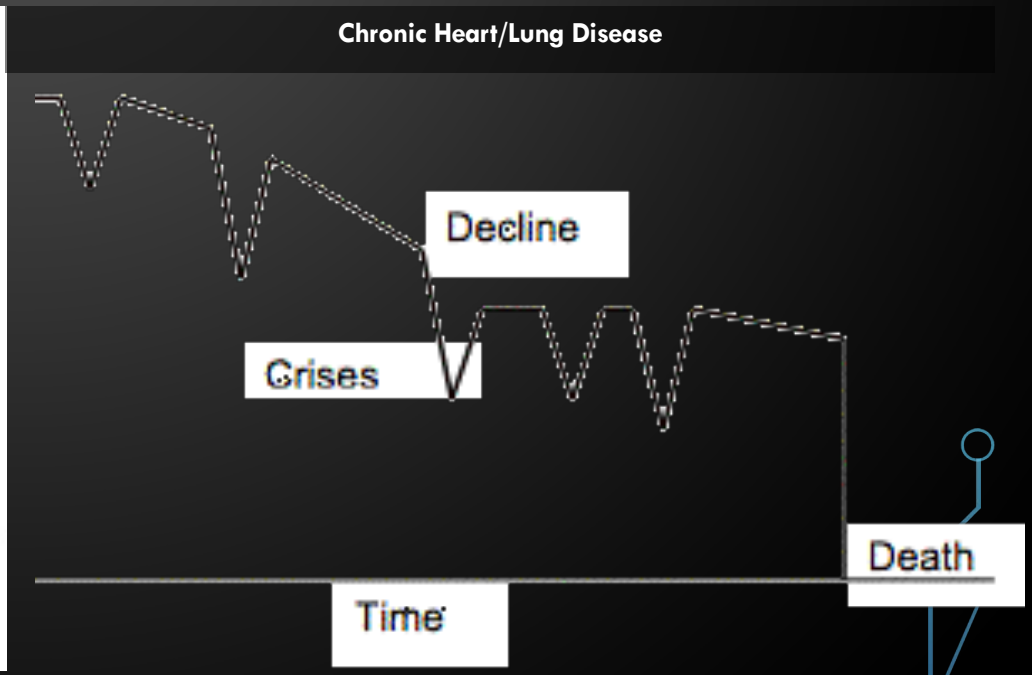
# Predictable Terminal Phase: Cancer




Resource: Field MJ, Cassel CK (eds), Institute of Medicine. Approaching Death: Improving Care at the End-of-life. Washington, DC: National Academy Press. 1997

# Unpredictable terminal phase



# MEDICARE HOSPICE CRITERIA

- FAST 7C and

The occurrence of at least one of six specified medical complications in the prior year:

- Aspiration pneumonia
- Pyelonephritis
- Septicemia
- Multiple decubitus ulcers ≥ stage 3
- Recurrent fever after antibiotics
- Inability to maintain sufficient fluid and calorie intake

**Table 1.** ADEPT Scoring in Nursing Home Residents With Advanced Dementia (N = 606)

| Characteristic | No. (%) of Nursing Home Residents | Points in Risk Score |
|---|---|---|
| Nursing home stay <90 d | 29 (4.79) | 3.3 |
| Age, y (per 5-y increment) | | |
| 65-69 | 7 (1.16) | 1.0 |
| 70-74 | 34 (5.61) | 2.0 |
| 75-79 | 61 (10.07) | 3.0 |
| 80-84 | 136 (22.44) | 4.0 |
| 85-89 | 171 (28.22) | 5.0 |
| 90-94 | 129 (21.29) | 6.0 |
| 95-99 | 56 (9.24) | 7.0 |
| ≥100 | 12 (1.98) | 8.0 |
| Sex, male | 110 (18.15) | 3.3 |
| Shortness of breath | 36 (5.94) | 2.7 |
| ≥1 Pressure ulcers at ≥ stage 2 | 33 (5.45) | 2.2 |
| Activity of daily living score = 28[a] | 256 (42.24) | 2.1 |
| Bedfast most of day | 59 (9.74) | 2.1 |
| Insufficient oral intake[b] | 252 (41.58) | 2.0 |
| Bowel incontinence[c] | 537 (88.61) | 1.9 |
| BMI <18.5[d] | 48 (8.28) | 1.8 |
| Recent weight loss[d,e] | 68 (11.70) | 1.6 |
| Congestive heart failure | 107 (17.66) | 1.5 |

Abbreviations: ADEPT, Advanced Dementia Prognostic Tool; BMI, body mass index, calculated as weight in kilograms divided by height in meters squared.

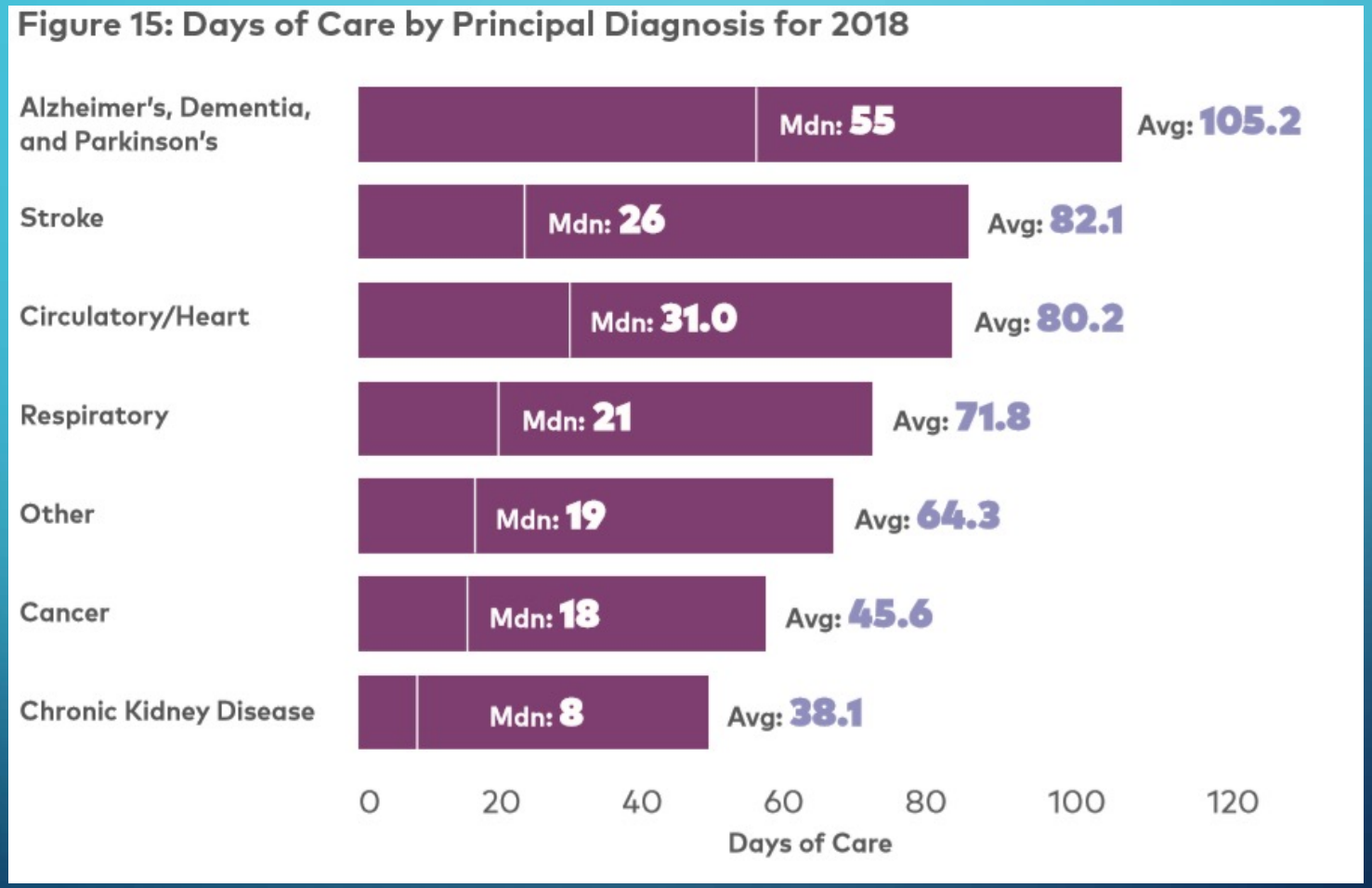
[a] Activities of daily living score (range, 0-28) is the sum of scores in 7 domains of function, including bed mobility, dressing, toileting, transfer, eating, grooming, and locomotion. Each is scored on a 5-point scale (0=independent; 1=supervision; 2=limited assistance; 3=extensive assistance; and 4=total dependence). A score of 28 represents complete functional dependence.

[b] Not consuming almost all liquids in previous 3 days or at least 25% of food uneaten at most meals.

[c] Occasionally, frequently, or always (vs rarely or never).

[d] BMI and recent weight loss are calculated with a sample size of 580 because a recent weight was not available for 26 nursing home residents.

[e] Recent weight loss is defined as more than 5% body weight in prior 30 days or more than 10% in prior 180 days.




www.nhpco.org/wp-content/uploads/NHPCO-Facts-Figures-2020-edition.pdf

# END STAGE DEMENTIA CONSIDERATIONS

- Care provided should be guided by goals of care rather than life expectancy
- Would you be surprised if this patient died in the next year?

# CHOICES, ATTITUDES, AND STRATEGIES FOR CARE OF ADVANCED DEMENTIA AT THE END-OF-LIFE

- disease trajectory and clinical course of advanced dementia;
- resident comfort;
- clinical decision-making;
- family satisfaction with end-of-life care, and

# CHOICES, ATTITUDES AND STRATEGIES FOR CARE IN ADVANCED DEMENTIA

- 323 nursing home residents with advanced dementia & HC proxies
- Followed for 18 months
- Endpoints
  - Survival, clinical complications, symptoms and treatments
  - Determine proxies understanding of prognosis and expected clinical complications

Mitchell, 2009

# CHOICES, ATTITUDES AND STRATEGIES FOR CARE IN ADVANCE DEMENTIA

- Mean survival 1.3 years; 55% cohort died by the end of study
- Distressing symptoms
  - Shortness of breath – 46%
  - Pain – 39%
- Other major acute illnesses were rare in last 3 months of life
- 40% had Burdensome Intervention ( hospitalization, ER visit, parenteral therapy or tube feeding) in last 3 months of life

# Choices, Attitudes and Strategies for Care in Advanced Dementia: Complications

| | Pneumonia | Febrile episode | Eating Problem |
|---|---|---|---|
| Patients affected | 41% | 52% | 85% |
| 6 month mortality | 46% | 44% | 38% |

Mitchell, 2010

# EATING PROBLEMS

- Apraxia and inattention complicate the task of eating
- Oral dysphagia - pocketing or spitting food
- Pharyngeal dysphagia  - delayed swallowing and aspiration
- Important to exclude reversible causes with acute onset:
  - Infection
  - Stroke
  - Medication side effects
  - Constipation
  - Depression

# EATING PROBLEMS

- Dysphagia and anorexia only become worse with disease progression
- High calorie supplements promote weight gain
- Appetite stimulants don't work
- No evidence that increased nutrition improves
    - Cognition
    - Function
    - Mortality

# TUBE FEED OR NOT TUBE FEED??

- Observational Studies show no improvement in
  - Survival
  - Nutritional status
  - Pressure Ulcers
  - Aspiration Pneumonia
- Risks of Feeding Tubes
  - Increased ER visits
  - Increased use of restraints
  - Increased risk for new pressure ulcers
- AAHPM, AGS & Alzheimer's Association discourage feeding tube placement

# PLEASURE FEEDINGS

- Providing food and drink for pleasure of patient.
- Benefits of hand feeding:
  - Pleasure of tasting food
  - Interaction with family members
- Strategies for Feeding
  - Minimize distractions
  - Sweets often preferred
  - Provide assistive feeding utensils/ finger foods
  - Ensure right consistency
  - Schedule when alert

# EMPOWERING CAREGIVERS: EATING PROBLEMS

- Offer Society recommendations when discussing eating problems
  - Reduces decisional conflict & increased overall knowledge
- Speech Evaluation / Dietary Consult
  - Provide hands on training . suggestions
- Online Resources : Dysphagia and Dementia

  https://geriatrics.jabsom.hawaii.edu/resources/

# PNEUMONIA: A COMMON COMPLICATION

- 41% had pneumonia
- 46% 6 month mortality
- 69% > then 1 episode

| | Pneumonia | Febrile episode |
|---|---|---|
| Patients affected | 41% | 52% |
| 6 month mortality | 46% | 44% |

# TREATMENT OF PNEUMONIA: COMFORT & SURVIVAL

**Table 2. Characteristics of 225 Suspected Pneumonia Episodes Among Nursing Home Residents With Advanced Dementia**

| Pneumonia Treatment | Pneumonia Episodes, No. (%) | % Alive 90 Days After Pneumonia Episode | SM-EOLD Score, Mean (SD) | No. (%) | | |
|---|---|---|---|---|---|---|
| | | | | Suspected Aspiration | Unstable Vital Signs[a] | Chest Radiograph Obtained |
| No antimicrobial agent | 20/225 (8.9) | 32.8 | 39.4 (4.4) | 12 (60.0) | 8 (40.0) | 6 (30.0) |
| Oral antimicrobial agent | 124/225 (55.1) | 64.5 | 34.0 (8.1) | 61 (49.2) | 33 (26.6) | 105 (84.7) |
| Intramuscular antimicrobial agent | 35/225 (15.6) | 56.7 | 33.7 (7.2) | 18 (51.4) | 18 (51.4) | 26 (74.3) |
| Intravenous antimicrobial agent or hospitalization | 46/225 (20.4) | 60.6 | 30.5 (9.3) | 35 (76.1) | 26 (56.5) | 36 (78.3) |

Givens, 2010

# EMPOWERING CAREGIVERS: INFECTIONS & FEVER

- Natural part of disease progression
  - Common pathway to death
- Treatment should be based on Goals of Care
- Comfort Measures
  - No antibiotics with aggressive symptom palliation
  - Trial of oral antibiotics
- Prolong Life:
  - Antibiotics  prolong life ~9 months
  - Oral/IM less burdensome

# HOSPITALIZATION IN END STAGE DEMENTIA

- ~15% of people with dementia die in hospital
- ~20% of nursing home patients had “burdensome” transfer near EOL
- Infections # 1 cause of hospital admission
- For people with comfort focused care
  - Do not hospitalize order is key

# POP QUIZ

- Careful hand-feeding for people with severe dementia is at least as good as tube-feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort. True
- Eligibility guidelines for admitting patients with dementia onto hospice accurately predict survival. False
- Treating pneumonia with antibiotics in people with severe dementia increases comfort levels. False
- Patients with dementia at end of life suffer a burden of symptoms similar to that of patients with cancer True
- Better counseling of health care proxies and advanced health directives are consistently shown to improve palliative care outcomes in people with dementia. True

# EMPOWERING PATIENTS & CAREGIVERS: AHCD

## CLINICIANS

- Dementia is terminal disease
- Educate on complications
- Revisit AHCD with disease progression

## HEALTH CARE PROXIES

- Start conversations early
- https://kokuamau.org
- Directives change with progression
- What is most important?

**Table 2.** Burdensome Interventions in Nursing Home Residents during Their Last 3 Months of Life According to Health Care Proxies' Understanding of Prognosis and Expected Clinical Complications.*

| Proxy's Understanding of Prognosis and Expected Complications | Residents Who Died during 18-Mo Study Period (N=177) | Residents Who Underwent Any Burdensome Intervention during Last 3 Mo of Life | Odds Ratio for Burdensome Intervention during Last 3 Mo of Life (95% CI)† | |
|---|---|---|---|---|
| | | | Unadjusted | Adjusted |
| | *no. (%)* | *no./total no. (%)* | | |
| Believed resident had <6 mo to live | | | | |
| Yes | 46 (26.0) | 14/46 (30.4) | 0.45 (0.19–1.04) | 0.34 (0.14–0.81) |
| No | 131 (74.0) | 58/131 (44.3) | Reference category | Reference category |
| Understood expected clinical complications | | | | |
| Yes | 146 (82.5) | 52/146 (35.6) | 0.30 (0.15–0.62) | 0.33 (0.17–0.63) |
| No | 31 (17.5) | 20/31 (64.5) | Reference category | Reference category |
| Believed resident had <6 mo to live and understood expected clinical complications | 37 (20.9) | 10/37 (27.0) | 0.13 (0.04–0.44) | 0.12 (0.04–0.37) |
| Either believed resident had <6 mo to live or understood expected clinical complications, but not both | 118 (66.7) | 46/118 (39.0) | 0.23 (0.10–0.57) | 0.25 (0.13–0.49) |
| Neither believed resident had <6 mo to live nor understood expected clinical complications | 22 (12.4) | 16/22 (72.7) | Reference category | Reference category |

* Burdensome interventions included any hospitalization or emergency room visit, parenteral therapy (administration of intravenous or subcutaneous hydration, intravenous antimicrobial agents, or intramuscular antimicrobial agents), and tube feeding. Of the 177 residents who died during the 18-month study period, 72 (40.7%) underwent at least one burdensome intervention in the last 3 months of life. CI denotes confidence interval.

† Both the unadjusted and adjusted odds ratios were calculated with the use of generalized estimating equations to account for clustering at the facility level. The adjusted odds ratios were also adjusted for pneumonia (in 66 of the 177 residents [37.3%]), febrile episode (57 [32.2%]), and other sentinel events, such as hip fracture (8 [4.5%]) in the last 3 months of life.

The NEW ENGLAND JOURNAL of MEDICINE

Mitchell, 2010

# SUFFERING IN CANCER VS DEMENTIA

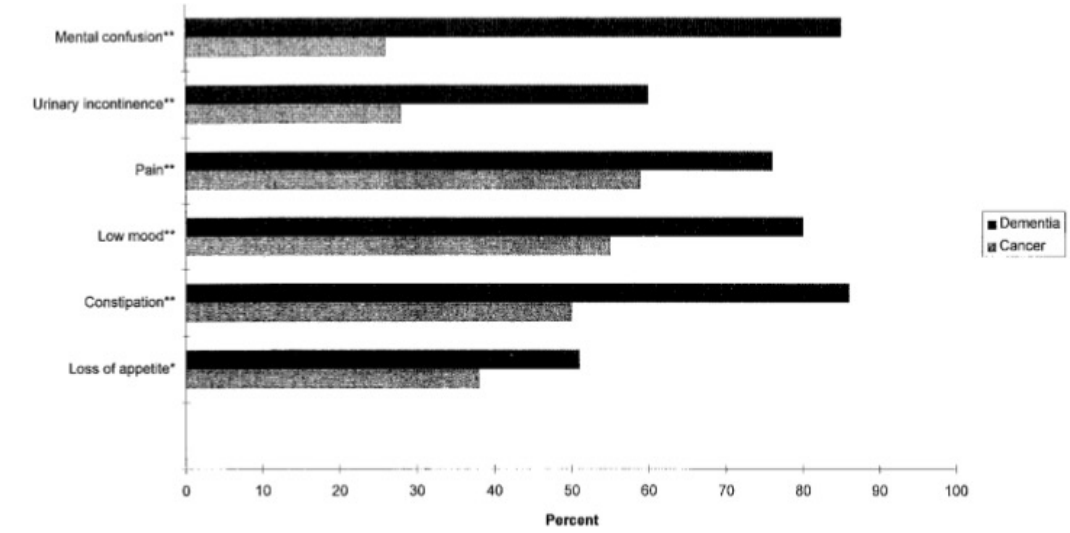



Fig. 1. Symptoms reported to have been experienced for at least 6 months by cancer and dementia patients in the last year of life

McCarthy, 1997

# SOURCES OF DISTRESS

- Assessing distress AD is difficult
- Tools available specific to AD
  - PAINAD
- GOC drive intervention

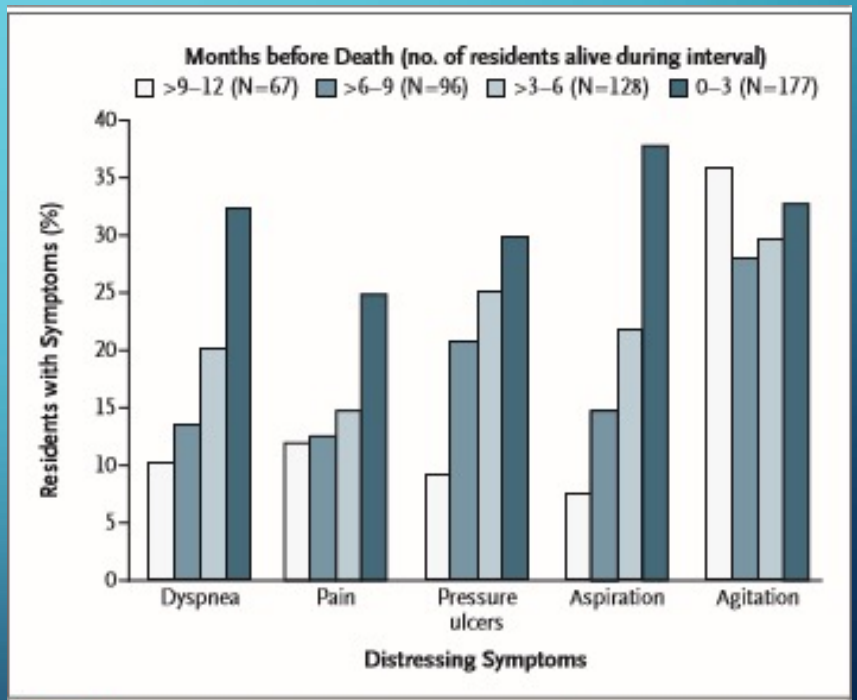



**Figure 3.** Proportion of Nursing Home Residents Who Had Distressing Symptoms at Various Intervals before Death.

Mitchell, 2009

# ASSESSING PAIN : PAINAD

- Observe for 3-5 minutes
- 1-3 mild pain
- 4-6 moderate pain
- 7-10 severe pain

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

(Warden et al., 2003)

# BENEFITS OF HOSPICE CARE: FOR PATIENT

- Increased assessment & treatment for pain and dyspnea
- Lower rates of physical restraints
- Lower rates of burdensome interventions
- Greater family satisfaction with care

Mitchell, 2012

# BENEFITS OF HOSPICE CARE: FOR CAREGIVERS

| | No Hospice | Hospice |
|---|---|---|
| Family wanted more information on what to expect while patient was dying | 22.5 | 11.1 |
| Family wanted more information regarding how pain was managed | 16.9 | 8.1 |
| Family wanted more information on what to do at time of death | 25.1 | 11.8 |
| Family wanted more help regarding spiritual and religious concerns | 10.6 | 7.3 |
| Family wanted more emotional support regarding their grief before patient's death | 22.7 | 14.0 |

Teno, 2011

# CONCLUSIONS:

- Educating Caregivers can impact burdensome interventions at end of life.
- Palliative Care should be introduced earlier in disease trajectory
- Treatment of complications should be guided by goals of care not prognosis.
- Hospice improves patient comfort and caregiver satisfaction during the dying process

# IT TAKES A VILLAGE (AND A FAMILY)

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# Mahalo

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