


## The Role of Palliative Care in the Demented Patient

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## OBJECTIVES

- Describe the Progressive Features of Dementia
- Review of Literature Progression of the Disease and Treatment
- Role of Palliative Care i.e. feeding, mechanical ventilation, comfort and "The Talk"

2

## SPECIAL THANKS

- Dr. Allison Jordan  
Medical Director of Palliative Care, Christian Hospital Northeast, St. Louis, MO
- Dr. Angelo Volandes, Dr. Aretha Davis, ACP Decisions
- Sara Ferguson, RN, Clinical Nurse Manager, Palliative Care, Senior Health, ImPACT, Spartanburg Regional Healthcare System
- Kensey Boyd, BS, Director of Quality and Compliance- Hospice, Palliative, Senior Health, Spartanburg Regional Healthcare System


3

"The necessity of nature's final victory was expected and accepted in generations before our own. Doctors were far more willing to recognize the signs of defeat and far less arrogant about denying them."

Sherwin Nuland, MD  
*How We Die*  
1993

4

## REFLECTIONS OF AN OLDER GENERATION



**"Bert, try not to live as long as I have, it's no fun anymore."**

Dr. Harry Rasor

1888 - 1982

5



**"Unfortunately, the disease will eventually win out,"**

said Dr. Nicholas Milano, a neurologist with the Medical University of South Carolina in Charleston.

6

## ALZHEIMER'S DISEASE



- The most common form of dementia
  - May be caused by plaques and tangles
- Not a normal part of aging
- Worsens over time
- 6<sup>th</sup> leading cause of death in the United States
- NO CURE

<https://www.alz.org/>

7

## ALZHEIMER'S DISEASE



- Will affect over 15 MILLION AMERICANS by 2050
- One in ten by age 65/ about 50% over 85
- Currently about 4 MILLION AMERICANS
- About 50% of patients in the NH have dementia
- 70% of patients with dementia will spend the last months of their life in a nursing home

8

## DEMENTIA



- A decline in mental ability severe enough to cause impairment in daily life
  - Memory
  - Communication
  - Ability to focus
  - Reasoning and judgement
  - Visual perception
- Term describes a group of symptoms
- Various causes: Vascular, thyroid, vitamin deficiencies

<https://www.alz.org/>

9

## DEMENTIA/NORMAL AGE CHANGES



- | <b>Dementia</b>   | <b>Typical Age-related Changes</b>   |
|---|--|
| <ul style="list-style-type: none"> <li>• Poor Judgment/ Decision making</li> <li>• Inability to manage budget</li> <li>• Losing track of date/ season</li> <li>• Difficulty having conversation</li> <li>• Misplacing things and being unable to replace steps to find them (keys in fridge)</li> </ul> | <ul style="list-style-type: none"> <li>• Making an occasional bad decision</li> <li>• Missing a monthly payment</li> <li>• Forgetting which day it is and remembering it later</li> <li>• Sometimes forgetting which word to use</li> <li>• Losing things from time to time</li> </ul> |

10

## DELIVERING BAD NEWS



- Delivering a diagnosis of dementia is a delivery of serious news
- Use SPIKES for communication
  - **S**etting
  - **P**erception
  - **I**nvitation
  - **K**nowledge
  - **E**motions
  - **S**ummarize and strategize

Baile et al. *The Oncologist*. 2000

11

## VIDEO DECISION SUPPORT



- Randomized Control Trial
- 200 Older Patients >65 (mean 75)
- Intervention: verbal narrative alone or video decision support
- Preferred Goal of Care:
  - Life Prolonging Care (CPR/MV)
  - Limited Care (Hosp.adm./Antibiot.)
  - Comfort Care
- Preferences after 6 weeks

*BMJ* 2009; 338:b1964, doi:10.1136/bmj.b2159

12

VIDEO DECISION SUPPORT

ADVANCE CARE PLANNING-6 WKS

- Verbal Narrative  
64% Comfort Care/19% Limited Care  
14% Life Prolonging Care/3% ???
- Video Group  
86% Comfort Care/ 9% Limited Care  
4% Life Prolonging Care/ 1% ????

BMJ 2009; 338:b1964, doi:10.1136/bmj.b2159

13

ACP VIDEOS



<https://vimeo.com/259348486>

northwell

Video compliments of Dr. Angelo Volandes, please do not duplicate, record, or use without permission.

DISEASE PROGRESSION

STAGE	COGNITION	FUNCTION
MILD	SHORT-TERM MEMORY	DRIVING/FINANCES
MODERATE	MEMORY/WORD FINDING COMPREHENSION	BATHING/DRESSING
SEVERE	LANGUAGE AND COMPREHENSION LIMITED	CONTINENCE WALKING
ENDSTAGE	UTTER FEW WORDS NO FAMILY RECOGNITION	EATING

15

PHARMALOGICAL APPROACH

- Cholinesterase inhibitors
  - Donepezil, galantamine, rivastigmine
  - Work by inhibiting the breakdown of acetylcholine by blocking the enzyme acetylcholinesterase
- Marginally effective
- Re-evaluate 12 weeks after starting
- Significant side effects

Birks, Cochrane Database, Syst Rev. 2006  
Courtney, et al. Lancet. 2004  
Cambell, et al. JAGS. 2017

16

LONG-TERM DONEPEZIL TREATMENT IN ALZHEIMER'S

- Randomized control trial/ 565 patients
- Community residents
- 12 week period randomly allocated donepezil 5mg/day vs placebo
- 486 completed were re-randomized to 5mg, 10mg or placebo
- Endpoints: institutionalized/ progression of disability

Lancet 2004; 363: 2105-15

17

LONG-TERM DONEPEZIL TREATMENT IN ALZHEIMER'S

Findings:

- No significant benefits were seen with donepezil compared to placebo in institutionalization or progression of disability
- No significant differences between donepezil and placebo in behavioral and psychological symptoms, caregiver psychopathology, final care cost, improved caregiver time, adverse events, deaths or between 5mg and 10mg donepezil

Lancet 2004; 363: 2105-15

18

BEHAVIOR MANAGEMENT

- Non-pharmacologic approach is first line to treat dementia-related behavior
- DICE
  - Describe the distressing behaviors
  - Investigate possible causes
  - Create a plan
  - Evaluate if plan has been effective

Kafes HC, et al. JAGS. 2014

BEHAVIOR MANAGEMENT

- Antipsychotics
  - Long-term increased risk of mortality
- Benzodiazepines
  - “Cocktail in a pill”
- Antidepressants
  - Citalopram may have a role in reducing agitation
- Dextromethorphan-quinidine
  - May help with agitation; increased risk of adverse events
- Restraints
  - Can worsen agitation

Ballard, et al. Lancet Neurol. 2009  
Porroneiro, et al. JAMA. 2014  
Cummings, et al. JAMA. 2015

ADVANCED DEMENTIA

- >80% of patients develop feeding difficulty
- They include:
  - Lose ability to feed oneself
  - Food refusal-won't open mouth/chew
  - Dysphagia-difficulty swallowing
- Like other terminal conditions weight loss is common and not easily reversible (CANCER/COPD/CARDIAC DISEASE)

SO WHAT ABOUT TUBE FEEDINGS ?????

THE ENJOYMENT OF FOOD IS SO AMERICAN AND YET...



SO WHAT ABOUT TUBE FEEDINGS ?????



PEG TUBES IN DEMENTIA

- Multiple studies in dementia patients show they DO NOT prolong life and MAY ADVERSELY DECREASE QOL (Decrease human interaction and increase restraints/ pressure sores)
- Denies Taste
- Reduces Dignity
- Adds caregiver responsibility with decreased personal connection

## GOOD NEWS!



Tube feedings in the United States nursing home residents with advanced dementia, 2000-2014

- Rates declined from 8.6% to 3.1% in white residents
- Rates declined from 37.5% to 17.5% in black residents

Mitchell, SL, et al. JAMA. Vol 316, 4. 769-770.

25

## BAD NEWS!



South Carolina is still near the top of the country in tube feeding rates in nursing homes.

Nationwide, mechanical ventilation rates are still a problem.



26

## MECHANICAL VENTILATION WITH ADVANCED DEMENTIA



*Association of Increasing Use of Mechanical Ventilation Among Nursing Home Residents With Advanced Dementia and Intensive Care Unit Beds*

- Attempted to describe the use and outcomes of mechanical ventilation and its association with increasing ICU beds in the US for patients with advanced dementia residing in nursing homes 120 days before hospital admission
- Study from 2000-2013, noted 635,000 hospitalizations of 380,000 patients (30.5% male, 69.5% female, mean age: 84)

JAMA Intern Med. Doi:10.1001/jamainternmed.2016.5964. October 2016.

27

## MECHANICAL VENTILATION WITH ADVANCED DEMENTIA



Findings:

- Use of mechanical ventilation increased from 39 per 1000 hospitalizations in 2000 to 78 per 1000 hospitalizations in 2013
- As the number of ICU beds in a hospital increased, patients with advanced dementia were more likely to receive mechanical ventilation
- Over the 10+ years, no significant improvement in one year mortality (65.2% vs 64%)

JAMA Intern Med. Doi:10.1001/jamainternmed.2016.5964. October 2016.

28

## PALLIATIVE PILOT IN SKILLED NURSING FACILITIES



Jan 2017 - June 2018

- 66 patients seen by APRN
  - 71% (15/21) changed to DNR from Full Code
  - 71% (25/35) hospice ordered of hospice appropriate
  - Prevented 26 readmissions

29

“Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need.”

Atul Gawande, MD

30

## PATIENT RESOURCES



Ira Byock, MD. *Dying Well: Peace and Possibilities at the End of Life*; (Riverhead Books,1997)

"EXTREMIS" Documentary film, ACADEMY AWARD NOMINEE featuring Critical Care Physician Dr. Jessica Zitter—Netflix/U-TUBE

Joe Klein. "How We Die," (*Time*: June 11, 2013)

Atul Gawande,MD. *Being Mortal: Medicine and What Matters at the End*; (Metropolitan Books, 2014)

Jessica Zitter, MD. *EXTREME MEASURES: Finding A Better Path to the End of Life*. (Random House,2017)

Nancy L. Mace. *The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease*

The Conversation Project ([theconversationproject.org](http://theconversationproject.org))

Prepare ([prepareforyourcare.org](http://prepareforyourcare.org))

31

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Kales HC. Management of Neuropsychiatric Symptoms of Dementia in Clinical Settings: Recommendations from a Multidisciplinary Expert Panel. *JAMA Geriatric Society*. 2014 April; 62(4):762-769

Robbins J. Comparison of 2 Interventions for Liquid Aspiration on Pneumonia Incidence. *Ann Internal Med*. 2008:148.509-518

Mitchell SL. *Advanced Dementia*. *N ENG J MED*. 2015;372;26:2533-2540

Dixon J, et al. The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People with Dementia and their Carers: A Systematic Review and Critical Discussion. *Journal Pain and Symptom Management*. 2018;55:132-150

Campbell ML; Guzman JA. A Proactive Approach to Improve End-of-Life Care in a Medical Intensive Care Unit for Patients with Terminal Dementia. *Critical Care Medicine*. 2004;32:1839-1843

32