

## Sensitive Issues in Palliative Care and Dementia

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Alzheimer Disease Symposium  
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- Mutual funds; no specific pharma or equipment stocks
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## A Case

- 69 year old woman with advanced Alzheimer disease (AD), no longer able to recognize family or perform any basic ADLs, residing in a nursing home for two years
- Typically physically restrained or sedated in order to control agitation / manage behavior
- After repeated antibiotic courses and admissions for infections, she dies in the NH, restrained, without family around, no specific palliative care measures in place

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## Outline for Presentation

- Background on palliative care, dementia, and challenges that make it especially difficult to provide excellent care to patients with advanced dementia and their families
- Suggest practical steps providers and families can take
- Review work being done on a promising pilot study: IN-PEACE

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## Definition of Palliative Care

- “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”
- “. . .intends neither to hasten or postpone death. . . .”

World Health Organization: <http://www.who.int/cancer/palliative/definition/en/>

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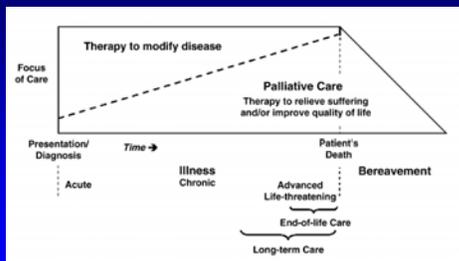
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## Palliative Care in the U.S.

- Main SUPPORT findings
  - Many in pain during hospital stays late in life
  - Advance directives / preferences unheeded
  - Families feeling unsupported, lives affected
  - Intervention (prognostic information and RN facilitating wishes) had no effect

J Am Geriatr Soc May 2000;48(5 Supplement)

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## Palliative Care in Indiana

- Die at home - 22.0%; hospital - 46.0%
- Persistent severe pain in NH - 42.3%
- Feeding tubes in NH residents with severe cognitive impairment - 17.1%

www.cher.brown.edu/dying/FACTSONDYING.HTM

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## Dementia

- Current estimate: over 4.5 million in US
- Projected for 2050: 13-16 million
- Conservative estimates: 1 in 3 women will develop dementia during her lifetime
- Outside estimate: Almost half of people over age 85 have dementia

Alzheimer's Association: [www.alz.org](http://www.alz.org)  
Hebert, LE. Archives of Neurology 2003;60:1119-1122

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## Dementia and Suffering

- Hospices in the U.S. reach less than 10% of patients dying with dementia
- Less than 2% of NH residents with end-stage dementia recognized as terminal
- 34% of NH residents with advanced dementia are tube fed (increasing over time)
- Dementia and NH residence are risk factors for under-treatment of pain

Sachs et al. J Gen Intern Med 2004;19:1057-1063  
Mitchell et al. Arch Intern Med 2004;164:321-6  
Lewis CL et al. J Gen Intern Med 2004;19:1034-8  
Bernabei et al. JAMA 1998;279:1877-82

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## Clinical Course of Advanced Dementia

- Prospective study of 323 nursing home residents with advanced dementia (16 NHs)
- Mortality 54.8% over 18 months
- 6-month mortality of 40% if pneumonia, febrile episode, feeding problems
- 40% with pain, dyspnea, burdensome Rx – but much less likely if proxy well informed

Mitchell et al. NEJM 2009;361:1529-38.  
Sachs GA. NEJM 2009;361:1595-96.

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## End-of-Life Care and Dementia: Why it's Even Harder

- Conceptual – is dementia a terminal illness?
- Communication, advance directives
- Working with families / proxies
- Prognostic uncertainty

Sachs et al. J Gen Intern Med 2004;19:1057-1063

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## End-of-Life Care and Dementia: More Challenges

- Problems identifying symptoms and titrating therapy
- Difficulty of withholding / withdrawing therapies such as antibiotics, tube feeding
- Institution / system constraints

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## Cancer Trajectory



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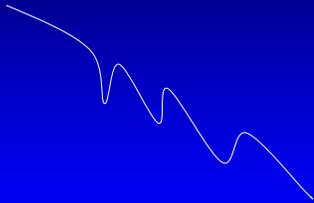
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## Dementia Trajectory



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## Palliative Care for Patients with Dementia: What Can We Do Now?

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## Advance Care Planning

- Dementia is currently an incurable, progressive illness that is eventually fatal
- Discussion over time about expected course and decisions likely to be confronted
- Goals of care – how we gradually shift mix toward emphasis on function and palliation
- Keep hospice in mind as an excellent option

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## Pain in Patients With Dementia

- Patients likely to have conditions or be receiving procedures that are painful
- No reliable evidence that pain sensation is diminished in dementia
- Strong evidence that pain is under-recognized and under-treated in older adults, nursing home residents, and patients with dementia

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## Assessing and Treating Pain

- Even patients with moderate dementia can report pain when asked
- Supplement patient report with that of caregiver plus direct observation (moving)
- Standing doses of analgesics plus breakthrough based on above; not PRN!
- Empirical trials of analgesics for challenging behaviors

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## Assessment of Pain

- Verbal report from patient
- Proxy report from family caregiver
- Observation of patient while moving, assessing for nonverbal pain indicators
- Train family caregiver in assessment
- Family caregiver trains us on patient's "pain signature"

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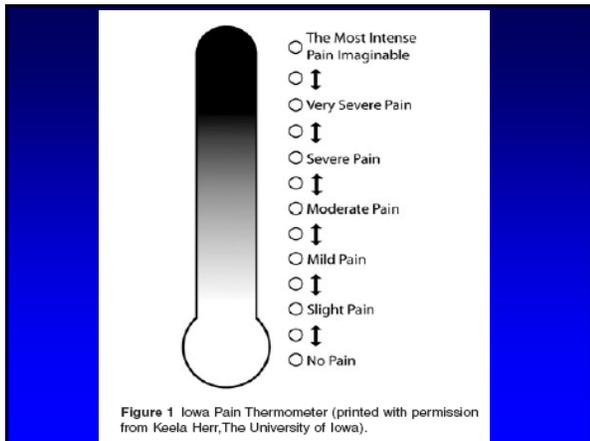
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## Pain Treatment

- Step 1: Acetaminophen (scheduled)
- Step 2: Tramadol (NSAID in few cases)
- Step 3: Opioid
- Additional considerations
  - Non-pharmacological
  - Adjuvant (e.g., anti-depressants)
  - Specific types of pain (e.g., neuropathic)

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## Tube Feeding Decisions

- No evidence for tube feeding:
  - Decreasing risk of aspiration
  - Improving nutritional status
  - Decreasing pressure sore risk
  - Prolonging survival (60% mortality at 6 months, perhaps 90% at one year)
  - Improving quality of life
- Recommend slow hand feeding

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## Tube Feeding: Hot off the Presses

- National study of nursing home residents with advanced cognitive impairment
- Great variation between states
- Hospital characteristics associated with higher rates: for profit status, larger size, and greater ICU use
- Lower rates with advance care planning
- Teno et al. JAMA. 2010;303(6):544-550.

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## From IN-PEACE Feeding Difficulties Protocol

- Depending on medical issues and stage of dementia, consider speech and swallowing evaluation (not needed for vast majority of patients)
- Instruct caregiver on diet modifications and feeding techniques (demonstrate if appropriate):
- Feed sitting upright, in chin tuck position
- Teaspoonful of food at a time
- Encourage double swallowing
- Sips of liquids in between bites
- From supervision/encouragement, to hand over hand, to hand feeding
- Modify solids: chopped to pureed and soft solids as needed
- Thicken liquids

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## From IN-PEACE: Feeding Difficulties Script

- “Often when we reach this point, families may ask if there are other, more effective ways to try and provide someone with nutrition and fluids. Some families ask about tube feeding, for example. Unfortunately, while that can be done, it does not have the benefits that one might hope. The research studies that have been done have failed to show feeding tubes help. Compared to patients who continue to be fed slowly by hand, patients with feeding tubes don’t really live longer, don’t have better nutrition, don’t get pneumonia less frequently, and don’t get fewer pressure sores.”

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## From the Alzheimer’s Association

- During the final stages of Alzheimer’s disease, hospice care can be particularly beneficial to individuals with Alzheimer’s disease and their family members. Hospice, which is normally offered to individuals who are expected to live less than six months, includes comprehensive palliative care and support services, including bereavement counseling for family members.
- Despite the appropriateness and benefit for persons with advanced Alzheimer’s disease and their families, and their eligibility for the Medicare hospice benefit, very few receive hospice care. Physicians, care professionals and families can change this by generating awareness of the importance of hospice to the individual in the final stages of Alzheimer’s disease.

[http://www.alz.org/professionals\\_and\\_researchers\\_end\\_of\\_life.asp](http://www.alz.org/professionals_and_researchers_end_of_life.asp)

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## Recognizing Hospice Eligibility

- FAST staging
- Weight loss – greater than 10% in six months (assumes being provided adequate calories and prior thoughtful assessment)
- Multiple pressure sores
- Repeated hospitalizations
- Feeding difficulties

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## The PEACE Program

- Palliative Excellence in Alzheimer Care Efforts
- Funding: Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care
- Goals: demonstration project to develop, implement, and evaluate a disease management model that integrates palliative care into the ongoing care of patients with dementia and their families throughout the course of the illness

Shega JW, Levin A, Cox-Hayley D, Sachs GA: Palliative Excellence in Alzheimer Care Efforts: The PEACE Program. J Palliat Med 2003;6:315-320.

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## PEACE Methods: Interviews

- Separate face-to-face interviews with patient (if capable) and caregiver
- Enrollment then q 6 months for two years; plus with caregiver following patient death
- Information from interviews:
  - Assess patient status (patient and proxy reports)
  - Assess caregiver status
  - Satisfaction with care, quality of care
  - Research nurses acted on unmet needs

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## Methods: After Death Measures

- Symptoms and care in last two weeks of life
- Location of care/death (was it location desired by patient?)
- Discussion of hospice option
- Enrollment in hospice
- Grief and bereavement issues

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## PEACE Results: Ongoing Care

- 97% of patients and 93% of caregivers rated the medical care as the best possible.
- 96% of patients and 86% of caregivers felt that everything possible was done to treat pain.
- 99% of patients and 98% of caregivers reported having confidence in the healthcare team.
- 92% of patients and 93% of caregivers felt the healthcare team was as helpful as possible.

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## Results: Final 2 Weeks

	PEACE (N = 34)	Non-PEACE (N = 101)	P values
Died at home	65%	54%	P = NS
Died in hospital	27%	30%	P = NS
Died in NH	9%	14%	P = NS
Desired location	79%	65%	P = NS
Pain rating (0-6, sd)	2.20 (1.94)	2.68 (2.18)	P = NS

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## Final 2 Weeks: Another View

	Hospice (N = 58)	Non-hospice (N = 77)	P values
Died at home	76%	38%	P < .001
Died in hospital	7%	45%	P < .001
Location of choice	90%	45%	P < .001
Mean pain rating	2.66	2.50	P = NS
Care rated VG/excellent	91%	56%	P < .001

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## Results: Final 2 Weeks

- “The doctors were very compassionate towards us when we were making hard decisions; they listened and never forced their opinion on us, which made me feel comfortable.”
- “The team approach [was done especially well]. They were attentive to my needs – always available to answer questions.”
- “The PEACE nurse, and even [these interviews have] helped me realize we did everything we could.”

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## Another Case

- 85 year old man with advanced AD, still ambulatory, but dependent in ADLs, little meaningful language, lives at home with wife
- Hospitalized once during last 3 years of life after a fall associated with URI and volume depletion
- Develops pneumonia, enrolled in hospice, dies comfortably at home with family surrounding him seven days later, symptoms well controlled

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## Limitations of Chicago Work: The Research Perspective

- Problems with ability to generalize, replicate
  - Highly specialized setting and providers with primary care provided by academic geriatrics group, many interested in palliative care
- Inadequate standardization / specification of intervention protocols
- No control group for comparison
- Data on care in last 2 weeks of life limited to recall by family members and is missing some items (e.g., financials, specific treatments)

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## IN-PEACE Pilot

- National Palliative Care Research Center – effort to catalyze palliative care research, position people for federal grant funding
- “Marriage” of PEACE content with:
  - Real world clinical laboratory of primary care practices
  - Collaborative care and self-management models
- Lead to definitive randomized trial
- Creating an intervention that is feasible for broad dissemination and of interest to payers, policy makers

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## Intervention Protocols

- **PREVENT (non-pharm)**
- Depression/anxiety
- Aggression/agitation
- Repetitive behavior
- Delusion/hallucination/paranoia
- Sleep disturbances
- Personal Care
- Mobility (incl wander, falls)
- **IN-PEACE (sx, choices)**
- Carry over from PREVENT
- Pain
- Other symptoms
- Feeding difficulties (including unintentional weight loss)
- Advance care planning
- Planning for hospice
- Navigating the acute hospital setting (avoiding aggressive defaults)

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### Help with BALANCE and WALKING

As memory loss progresses, your loved one may become stiff or awkward, may develop stooped or leaning posture or a shuffling walk. This is due to damaged areas of the brain which control muscle movement.

Tell your health care provider about any change in walking posture, stiffness, repetitive motions, or falling. This may be due to memory loss or there may be a reason that can be treated.

- ▶ Put away scatter rugs.
- ▶ Consider which works better and then provide shoes with either smooth or rubber soles.
- ▶ Pad steps and corners of furniture.
- ▶ Chairs and furniture should be stable and sturdy.
- ▶ Get things out of the way.
- ▶ Simplify traffic patterns in the home.
- ▶ Install grab bars and handrails in the bathroom.
- ▶ Have your loved one take your arm when walking. Hold your arm close to your body.
- ▶ If your loved one can't learn to use a cane or walker properly, then it is safer not to use it.

Reprinted from the Alzheimer's Association's "Help with Balance and Walking" brochure.

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**For the Caregiver**

*You cannot take care of anyone else if you don't take care of yourself first.*

Remember to:

- Get plenty of rest
- Eat right 
- Drink 8 glasses of water a day
- Take a walk every day & include your loved one 
- Keep your prescriptions filled
- Take your medications as prescribed
- Make time for yourself! Take regular breaks from caregiving – at least 8 hours a week is ideal, but even an hour or 2 can help you recharge.
- Keep your own doctor's appointments. Plan ahead to arrange transportation and get someone to stay with your loved one. 

Don't put your own health on the "back burner."

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**HELP with DRIVING**



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**Summary**

- Palliative care in the U.S. and Indiana still has a lot of room for improvement.
- Improving palliative care in dementia: especially challenging due to conceptual, clinical, system issues.
- Excellent palliative care in dementia: achievable with commitment to palliative care & close monitoring under a PEACE-like model with hospice.
- Much one can do while awaiting IN-PEACE

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