



# PALLIATIVE CARE FOR PERSONS LIVING WITH DEMENTIA

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# **HADI** Hawai'i Alzheimer's Disease Initiative

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# Goals of this presentation

- Help you understand the course of dementia
- Describe the unique approach of palliative care – and how it differs from “usual care”
- Explain the challenges of navigating the health care system when you have dementia
- Convince you that palliative care is the best “framework” for care of people living with dementia
- Encourage you to consider how you might apply this information where you work, or with people you know.

# What is Palliative Care?

- **Specialized care for people with serious illnesses.**
- Focus on improvement of symptoms and better quality of life for the patient and the family/caregivers.
  - At any phase of the disease
  - Can be provided simultaneously with curative treatments
  - Involves a multi-disciplinary team – nurses, doctors, social workers, clergy, etc. Works alongside other parts of the medical team so previous medical relationships are maintained and honored.
  - It's a LOT more than pain management
  - Focus on advance care planning and patient preferences is a hallmark of this type of care.



# What is dementia?

- A group of symptoms (usually including memory impairment) that affects thinking and social abilities severely enough to impair one's ability to function independently.
- Dementia Syndrome ?
- Over 5 million Americans currently have dementia - but many fewer have been formally diagnosed.
- There are approximately 2 million people in the U.S. with advanced dementia and are dependent on others for all their activities of daily living.
- Research suggests that more than 15 million Americans are full or part-time caregivers for someone with dementia

# Dementia is unique

- While many other conditions do not have cures or effective treatments- persons with dementia usually lose insight into their disease as it progresses.
  - This means greater caregiver burden, and greater costs for both formal and “informal” care.
  - This means less ability to ask the person what their preferences for care are over time

# Health care providers

- Rarely discuss advance care planning with persons living with dementia – it's hard!
- Struggle to find time/opportunity to speak with caregivers when patient isn't present
- Even more rarely discuss end of life care
  - Feeding issues, infections, falls, and common things to expect
- Doctors routinely over-estimate prognosis

# Why palliative care rather than usual care?

- Focuses on patient preferences and quality of life
- We spend a tremendous amount of money on “usual” care for persons with dementia - with poor outcomes as measured by families and by traditional measures.
  - 75% of hospitalizations may be medically unnecessary or are discordant with patient preferences
  - pacemakers placed in PWD at almost twice rate of non-demented patients
  - survival after hip fracture and pneumonia is very poor in persons with advanced dementia
  - 16% of persons w dementia die in hospitals
  - 20% of persons in LTC w adv. dementia had a burdensome transition near the end of life
- Research shows that symptom management is generally poor for people with dementia.
  - Less medication for hip fracture than non-dementia patients



# Palliative care for early/moderate dementia

- **Advance care planning** – discuss disease progression with patient or with caregiver if patient not able or willing to participate. Delicate but honest conversation.
  - Support system as disease progresses – bring up caregiver stress
  - Safety: cooking, driving (plan for retirement), wandering, finances
  - Goals of care:
    - What is your definition of quality of life?
    - If you were not able to have that, what kind of care would you like?
  - Choices of medications
    - Do you want medications designed for life prolongation – making severe dementia more likely?
      - Discuss cholesterol, hypertension, diabetes drugs – pros and cons.
  - Plan for hospitalizations – Explain that physical deterioration occurs – not just brain.
    - Use scenarios of common problems: Falls, infection, stroke, MI

# Specialized directives for dementia !

- [Dementia-directive.org](http://Dementia-directive.org)
- Developed by Dr. Gaster at Univ. of Washington
- Mild, moderate, adv. dementia description then choices -
  - To live for as long as I could. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.
  - To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

# More dementia advance directives

- To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill. If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.
- To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness. I would not want any care that would keep me alive longer.

# Dementia is a terminal illness

- Causes of death include those that are sudden –
  - Accident, falls, heart attack, stroke or infection
- And those that have slower onset
  - Weight loss/eating problems, malnutrition, recurrent infections, organ failure, non-compliance with medical treatments for other diseases.
- Prognosis is difficult
  - Especially in early and moderate stages of the process
    - Even in severe dementia, it is hard to tell when someone is within 6 months of dying (hospice criteria)



# Issues in advancing dementia

- Ongoing discussions about Goals of Care with family and caregivers
  - Goals of care WILL change over time – need to keep asking
  - How should we treat the OTHER diseases – treatment causes burden and discomfort for many patients. (blood draws, finger sticks, diets)
  - What medications to offer and what are the side effects/burden of administration?
- Explicit discussions about caregiver burden and its consequences
  - Health consequences are real for caregivers. Also, bankruptcy, loss of job, loss of retirement income, are all consequences of caregiving.
- More detailed discussions of finances and care options
  - “the promise” and why we should discuss it honestly as disease progresses.

# Hospitalizations and advanced dementia

- The ultimate “square peg in a round hole” because hospital processes are not designed for a person with dementia.
- Delirium and falls are much increased with hospitalization.
- Family involvement and constant presence is a big factor in avoiding hospital complications – a hospitalization cannot be a “break” for caregivers.
- People with advanced dementia are more often hospitalized than those without dementia – but with worse outcomes.
- **Share your experience:** “I’ve noticed that most people with advanced dementia don’t rebound to their previous level of functioning after a hospitalization”



# More about hospitalization...

- 6 month mortality is greatly increased (over non demented controls) with hospital admission for hip fracture or pneumonia (about 1/2 of study group had died within 6 months of hospitalization).
- We should be aware the hospital doesn't really "fix" the major problem, and may worsen outcomes. Families don't hear this message – and even if they do, our system is not designed to help them in other ways.
- **All paths seem to lead to the hospital.**

# Acute illness challenges...

- Why?
  - Barriers to get in to the PCP quickly
  - ER is default – caregiver under stress!
  - Hard to get home nursing quickly to provide IV's or meds
  - We have to be able to respond quickly with mini “hospitals at home” to prevent hospital admissions.
- Longer hospital stays and frequent re-admissions are much more common for people with advanced dementia.

# Pain management

- As communication abilities deteriorate and a person's ability to remember how often or how severe their pain WAS... then likelihood of good pain management declines.
  - Dynamic (real time) assessment strategies
  - Scales that use facial expressions or other methods
  - Trials of medication – prescribe differently, more scheduled dosing
- Studies have shown PWD get less pain medication for given diseases – but certainly do have same amount of pain for the same diagnosis.
- Pain can be a source of agitation and challenging behaviors (yelling, pacing, restlessness) – and trial of treatment for pain is suggested.

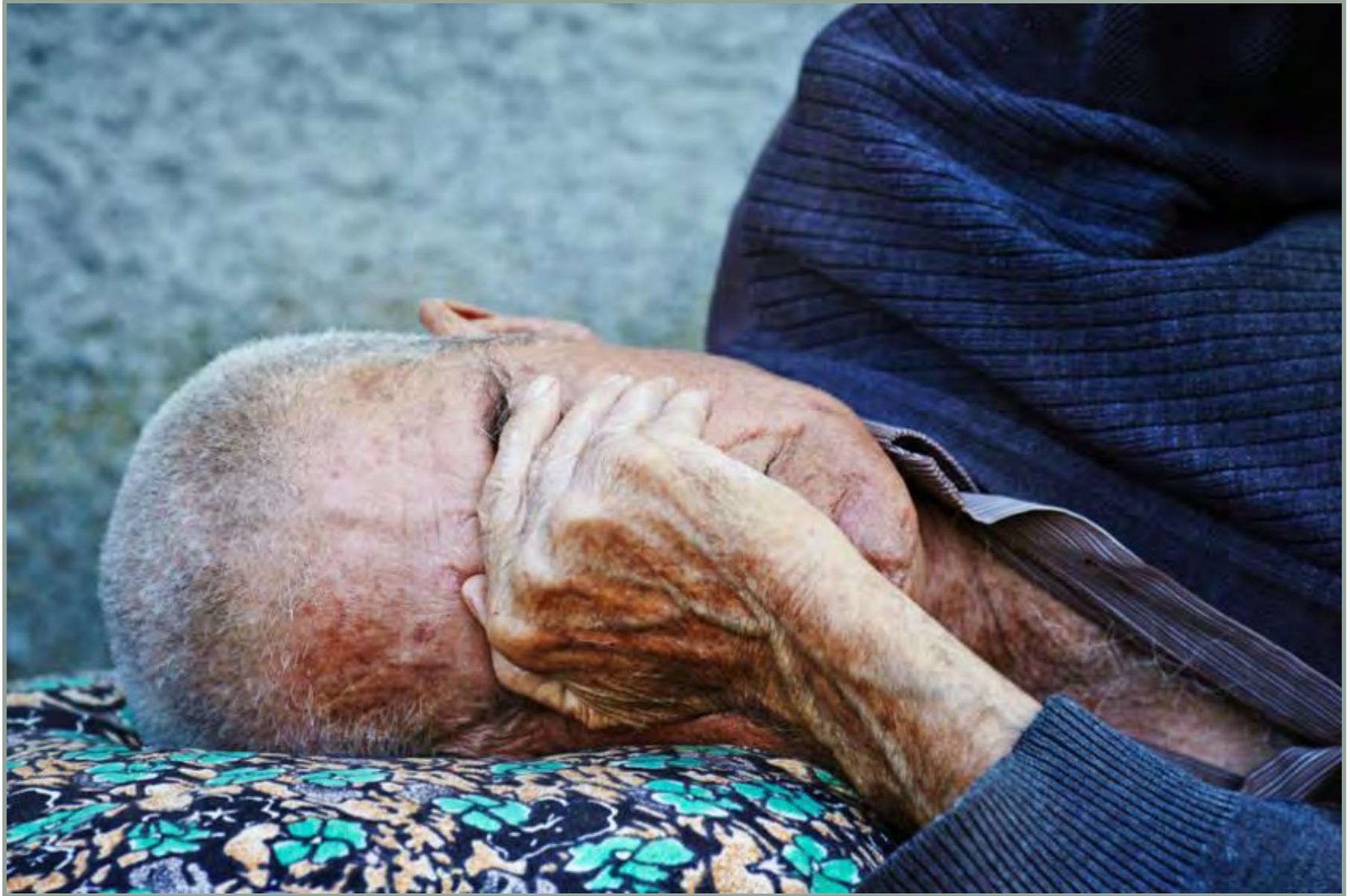


# Weight loss and eating problems

- Difficulty swallowing is caused by the disease over time
  - Many good strategies and approaches are available to help a PWD enjoy the taste of food and try to prevent weight loss.
- Weight loss can occur even with good intake of calories
- Feeding tubes are not the answer
  - NO consistent evidence of longer survival, less pneumonia, improved skin healing or improved quality of life for the patient.
- Yet – the system has fiscal rewards for use of feeding tubes
  - Increased reimbursement for LTC (changing)
  - More tubes placed by larger hospitals, for profit hospitals, and by sub-specialist doctors than by primary care/geriatrics.

# Fevers and infections

- More common as dementia advances – why?
  - Less awareness of early symptoms
  - Increased risk of aspiration and pneumonia
  - ? Alteration of immune system due to stress or disease itself
- Antibiotics are given frequently- especially in nursing home patients
  - 2008- over 18 months at 21 LTC facilities
  - Average was 4 courses of Abx per patient w adv. dementia
  - **Many patients die “while taking” antibiotics**
  - Significant contributor to antibiotic resistance
- Decision to treat w antibiotics
  - Oral treatments may be as effective – but sometimes harder to do in home setting (caregiver burden, fear of the illness, isolation)



# System barriers to good palliative care

- Hospitalizations raise likelihood of movement to SNF care
- In 2006, 40% of patients who died in long term care with advanced dementia had used SNF benefit in last 90 days of life.
  - This means no access to hospice care (can't have SNF/hospice)
  - Ultimately shorter hospice stays when they do enroll
  - With hospice care a much decreased likelihood of death in a hospital bed.
- No structured system for palliative care – hard to access, especially in the outpatient setting, despite evidence of benefit.
- Heroic caregivers have few options when dealing with an acute illness or distress... Emergency Room is often only option.

# Palliative care for dementia

- Makes sense because of terminal disease process and emphasis on discussing goals of care and quality of life as a priority. Helps make a “plan” rather than a reaction.
- “Usual” medical care is a poor fit for a person with dementia – but currently there are few options.
- Very little incentive for providers to spend time with families to discuss important issues – Advance Care Planning code for provider reimbursement is helping.
- Our systems should be re-designed to promote palliative care throughout the disease process.
  - Improved satisfaction, more caregiver support
  - More options for care outside a hospital or nursing home

- In absence of a cure, a palliative approach to care can have a significant and profound positive impact not only on the life of the person with dementia, but for their families and friends, and for staff as well.

# Questions/discussion ?

