Objectives of this presentation

1. The learner will define dementia and list 3 stages of Alzheimer’s disease
2. The learner will identify 3 palliative nursing interventions related to caring for a person with dementia
3. The learner will verbalize when a person with dementia may benefit from hospice care
What is dementia?
• Dementia is considered a syndrome
• Dementia is characterized by a decline in a person’s memory, language, problem-solving and other cognitive skills that affect a person’s ability to perform everyday functions
• Classified as major neurocognitive disorder

Common causes of dementia
• Alzheimer’s disease
• Vascular dementia
• Dementia with Lewy bodies
• Parkinson’s dementia
• Mixed disease
• Frontotemporal lobar degeneration

Stages of Alzheimer’s disease
• Mild cognitive impairment as a potential precursor
• Mild Alzheimer’s (early stage)
• Moderate Alzheimer’s (middle stage)
• Severe Alzheimer’s (late stage)
Assessing the disease trajectory with Alzheimer’s

- Symptoms advance from mild to moderate to severe at a varying pace and give insight into where the person is on this long trajectory
- More advanced: people need help with bathing, dressing and eating, lose their ability to communicate verbally, fail to recognize loved ones, and need around-the-clock care

Throughout the course of disease

- Two concepts are woven throughout any stage of Alzheimer’s:
  - Need for supportive, frequent conversations with the potential or activated surrogate decision-maker
  - Understanding ethical dilemmas such as safety vs. autonomy

Throughout the course of disease

- Goals of care conversations
  - Goals, values, wishes
  - Long term care plan
  - Financial planning, cost of care

- Advance directives
  - Health care proxy
  - MOLST/POLST
Throughout the course of disease

- The ethical principles of safety and autonomy often clash in older adults
- What if Maslow was wrong?
- Respecting wishes and values
- Ways to preserve autonomy
- Safety issues

Common signs, symptoms and challenges early in the disease

- Challenging behaviors
- Increased incidence of depression
- Symptoms that might occur with co-morbid chronic conditions

Challenging behaviors

- What are challenging behaviors?
- What do they signify?
- What causes these behaviors?
- How do we respond?
2 helpful nursing theories

- Needs-driven, dementia-compromised nursing theory (Algase, 1996)
  - Explains the unique source of needs for the person with a dementia
  - Behaviors must be viewed as an expression of a person’s unmet needs
- Progressively lowered stress threshold theory (Hall and Buckwalter, 1987)
  - Behaviors have triggers
  - As disease progresses, lowered doses of triggers produce the stress response
  - Responsibility to modify the environment

Approach to caring: a supportive environment

- Role of the brain’s amygdala
- Alzheimer’s Association habilitation theory of dementia care
- Limiting experiences that cause distress
- Encouraging experiences that promote comfort, happiness, and connection

Approach to caring: recognizing the person

- Supporting personhood
- The person’s life story:
  - Culture change movement in nursing homes: person-centered or person-directed care
  - What caregivers should know
- The power of reminiscence
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**Depression, delirium and dementia**
- Differentiating between depression, delirium and dementia
- All affect a person’s ability to perform everyday functions
- All produce psychological suffering

**Depression**
- Definition
- Assessment
- Treatment options
- Risks and benefits in treatment

**Delirium**
- Definition
- Assessment
- Treatment options
- Risks and benefits in treatment
Common complications and co-morbid conditions
• Skin integrity
• Incontinence
• Infections
• Nutrition

Pain
• Definition
• Assessment
  ◦ PAINAD (pain assessment in advanced dementia)
  ◦ PACSLAC (pain assessment checklist for seniors with limited ability to communicate)
• Treatment options
• Risks and benefits in treatment

FDA approved medications for the treatment of dementia
• Acetylcholinesterase inhibitors
  ◦ Donepezil, rivastigmine, galantamine
  ◦ Indication: mild to moderate stage dementia
  ◦ Action: prevents the breakdown of acetylcholine in the brain
  ◦ Side effects: all have GI s/e of n/v/d/abdominal cramping, loss of appetite, insomnia, agitation, fatigue
  ◦ Rivastigmine, galantamine must be used cautiously in patients with peptic ulcer disease, asthma and bradycardia
  ◦ Benefit: slows the progression of disease
### FDA approved medications in the treatment of dementia

- **N-methyl D-aspartate (NMDA)**
  - **Namenda**
    - Indication: moderate to severe Alzheimer’s disease
    - Action: blocks the toxic effects associated with excess glutamate and regulates glutamate activation
    - Side effects: dizziness, constipation, confusion
    - Benefits: improve memory, awareness, and improve daily functioning

### Medications to avoid in Alzheimer’s dementia

- Benzodiazepines
- Anticholinergics
- Zolpidem

### Common signs, symptoms, and approaches to care in advanced disease

- How do we prognosticate?
  - Pneumonia, febrile episodes and eating problems represent a natural progression of the disease process and indicate a transition from advanced dementia to end of life
  - 6-month mortality: near 50%
2 most common symptoms in advanced dementia

- Swallowing problems
- Infections

Why do these develop in end stage Alzheimer’s and other diseases that cause dementia symptoms?

Dysphagia

What we now know:

- People with advanced dementia often experience eating difficulties due to the **progressive neurodegenerative process**
- Eating difficulties are considered a **natural part of the disease process** and, when persistent, characterize the end stage of dementia

When feeding problems emerge

- Evaluation of the resident
- Altering food texture, viscosity, temperature, density?
- Environmental modifications
- Continuing discussion with family about course of end-stage dementia and goals of care
A timely need to revisit the goals of care discussions

- Goals of care discussions with surrogate decision-makers in advanced dementia should include:
  - Sharing the concepts of dementia as a terminal illness, the disease trajectory and the likely patient response
  - Identifying the choice of goals as comfort, living longer, or somewhere in between
  - Defining what each goal path would look like
  - Discussing approaches to care for eating problems, infections, and possible hospital transfer as aligned with the person’s goals of care

HPNA position statement

“At some point in an illness trajectory, most patients will be unable to take food and fluids by mouth or will refuse food”

- Focus on how to enhance the patient’s comfort

American Geriatrics Society position statement

- Feeding tubes not recommended for older adults with advanced dementia
- Efforts to enhance oral feeding by altering the environment and creating patient-centered approaches to feeding should be a usual part of care
- Tube feeding is a medical therapy that a surrogate decision-maker can decline or accept
- Health care institutions should not impose obligations or exert pressure to institute tube feeds
Issues with feeding tubes

• Feeding tubes don’t prevent aspiration, heal pressure injuries, prevent weight loss or malnutrition
• Risks and complications with feeding tubes are many
• Why, then, are there such a large number of feeding tubes placed and a low prevalence of orders to forego feeding tubes?

Alternatives to tube feeding

• Comfort-feeding only (CFO) order with individualized feeding care plan
  ▪ Comfort means the stopping point in feeding
  ▪ Individualized care plan with continued attempts to hand feed the patient
  ▪ Comfort as overarching goal of care
• Careful attention to dry mouth and sensation of thirst

Recurrent infections

• Common infections are pneumonia, urinary tract infections, and infections associated with pressure ulcers
• ½ of the patients with advanced dementia receive a diagnosis of pneumonia in their last 2 weeks
• Pneumonia most commonly identified cause of death in this population
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Treatment choices with infections
- Antimicrobials, comfort, both?
- The risks and burdens
- The benefits
- Treatment options need to be weighed in the context of the person’s overall condition and goals of care
- Palliative treatment should be focused on symptomatic relief and eliminating suffering

Rehospitalization?
- The risks and burdens?
- The benefits?
- For the person with advanced dementia, transition to the hospital is burdensome
- An estimated 75% of hospitalizations may be unnecessary, or not in alignment with the person’s goals in advanced dementia
- Advance care planning is key

General nursing approaches
- Medications: simplify
- Diet: liberalize
- Interventions causing distress: reduce or eliminate
- Use of invasive tubes: question their use
- New diagnostic work ups: assess risk and benefits
- Basic needs: anticipate and meet basic needs
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The family experience

• Who is the ‘family’?
• What is the family experience?
• Times of critical transitions?
• How best do we support family members?

What does the family experience?

• Caregiver tasks
• Caregiver burden and fatigue
• Impact on the physical well-being
• Impact on social and spiritual well-being
• Changing roles: from togetherness to aloneness
• Living with an uncertain future

Times of greatest transition

• Early in the disease as cognitive changes become evident
• During the time of diagnosis
• Becoming a nursing home ‘visitor’
• Becoming a grieving survivor
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**How best do we support the family?**
- Community services, respite
- Partnering with the family
- Information and support
- Help in easing the burden of decision-making
- Increased national awareness with the National Plan to Address Alzheimer’s Disease

**When is it time for hospice?**
- Medicare’s program for end of life
- Provides care in the home, nursing facility and free standing hospice residences
- Shown to improve quality of life through better symptom management, fewer hospitalizations and greater family satisfaction
- General criteria to qualify
  - patient has a 6 month prognosis confirmed by two MD’s
  - patient is not pursuing curative care

**Disease specific hospice criteria**

**Alzheimer’s dementia**
- Functional Assessment Test (FAST) stage 7 and beyond
- Unable to ambulate
- Unable to sit up unassisted
- Inability to smile
- Able to speak only a few intelligible words
- Speech limited to one word
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Additional criteria for hospice; one episode within the past 12 months
- Aspiration pneumonia
- Pyelonephritis or other upper urinary tract infection
- Septicemia
- Pressure ulcers, multiple, stage 3-4
- Fever, recurrent after antibiotics
- Inability to maintain sufficient fluid and calorie intake with 10% weight loss during the previous six months or serum albumin < 2.5

Barriers to high-quality end-stage dementia care
- Failure of the imagination:
  - "The professional caregiver’s inability to perceive that their care with patients matter, and their inability to recognize that how they treat people with advanced dementia will have a profound impact on their patients’ lives, for better or worse” NHPCO
- Losing sight of our goals:
  - Promoting and enhancing quality of life
  - Promoting and maintaining dignity
  - The art of being present

“You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also live until you die”.

Dame Cicely Saunders, Founder of the hospice movement