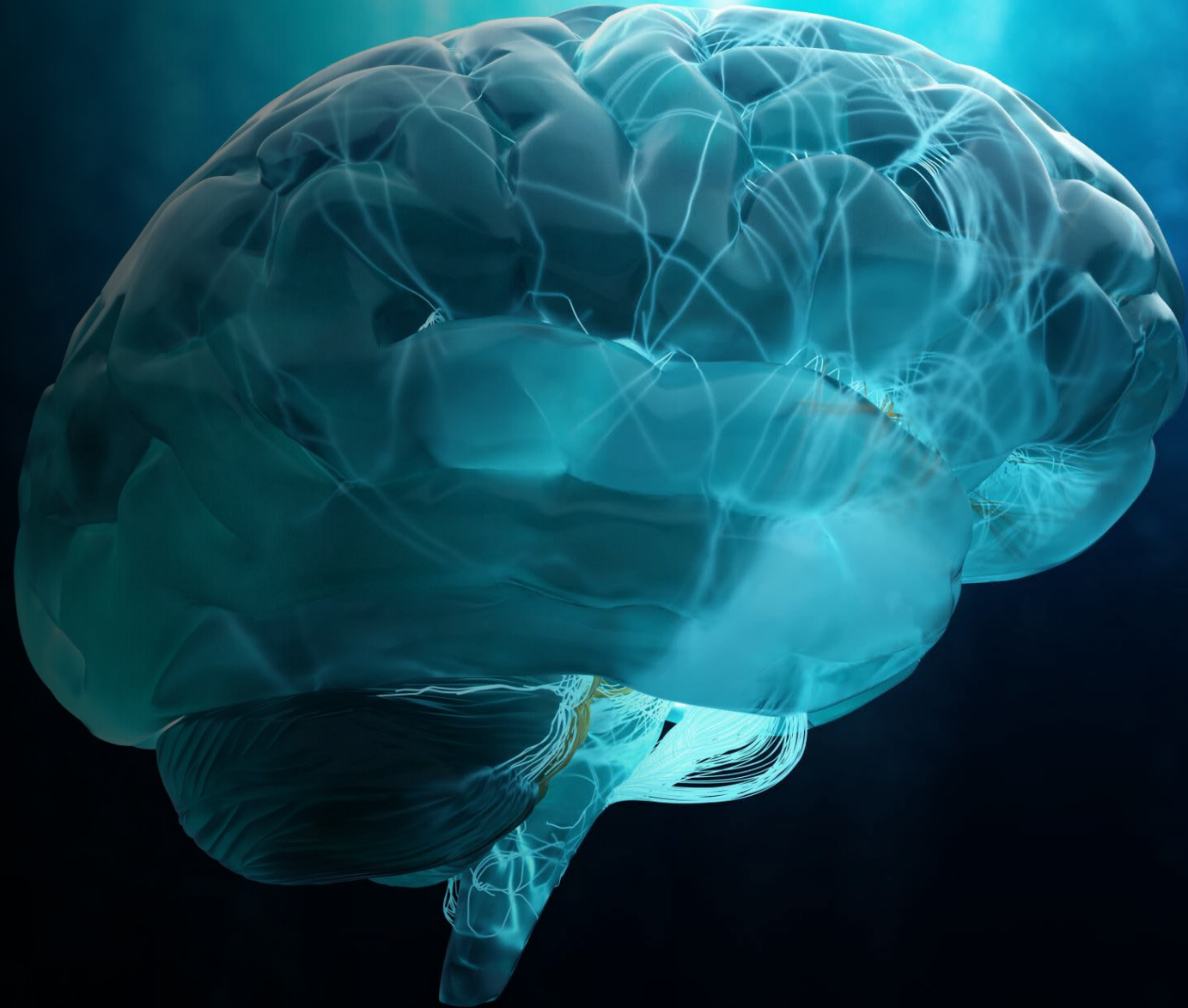




Palliative Care in Patients with Dementia

Meenakshi Singh, MD
Hospice & Palliative Care Fellow



Learning objectives

- What is Dementia?
 - ✓ Diagnosis
 - ✓ Subtypes
 - ✓ Stages
- Advance Care Planning
- Dementia-related care decisions
 - Artificial Feeding
- Palliative Care vs. Hospice

A close-up photograph of an elderly woman's face, focusing on her right eye which is a striking blue color. Her skin is heavily wrinkled, particularly around the eye and forehead, indicating her advanced age. The lighting is soft, highlighting the texture of her skin.

— Lucy's Story:

- Lucy is an 81 y/o woman with arthritis, HTN, brought in by her son, Patrick, who has concerns about her memory. Lucy is widowed and lives alone in her house with her 2 cats.
- Recently, Lucy was found wandering in the parking lot of a mall, looking for her car. Lucy's neighbor called Patrick, who lives in a different state.
- When Patrick arrived, he noticed that his mother is becoming increasingly forgetful, repeatedly asking the same questions, and is misplacing things often.
- Lucy's telephone line has been cut off since she forgot to pay her bills. When asked about these concerns, Lucy became defensive and agitated.

A close-up photograph of an elderly woman's face, focusing on her right eye which is a striking blue color. Her skin is wrinkled and aged, with visible lines around the eye and forehead. The lighting is soft, highlighting the texture of her skin. The background is dark and out of focus.

— Lucy's Story:

- Lucy was diagnosed with moderate stage dementia and started on Donepezil 5mg daily, with a plan to increase the dose to 10mg daily after 4 weeks.
- Patrick has taken a leave of absence from work while he decides how to best take care of her. He is managing Lucy's finances, meals, medications, and transportation.
- Patrick is also feeling overwhelmed and faces many care related decisions.

What is Dementia?

- **Dementia is a progressive deterioration of the brain**
- It affects cognitive functions such as memory, reasoning, communication, and the ability to perform daily activities.
- Common symptoms:
 - ✓ **Memory loss:** Difficulty remembering recent events, names, and faces.
 - ✓ **Difficulty in communication:** Problems with language, such as finding the right words or understanding speech.
 - ✓ **Impaired reasoning and judgment:** Difficulty making decisions, solving problems, or assessing risks.
 - ✓ **Impaired visual perception:** Difficulty interpreting visual information, which may affect spatial awareness.
 - ✓ **Personality and behavior changes:** Changes in mood, personality, and behavior may occur, leading to confusion, irritability, or social withdrawal.

Dementia Diagnosis

Dementia is more common in older adults, but it is not a normal part of aging.

Dementia diagnosis involves a combination of

- medical history and physical exam
- cognitive assessments (e.g. MMSE),
- laboratory tests
- imaging studies

Dementia Subtypes

Alzheimer's Dementia (60-80%)

- Insidious onset
- Early stage - short term memory loss
- Middle stage - psychosis
- Late stage - dependence in ADLs

Vascular Dementia (10-20%)

- Stroke, step wise decline

Lewy body Dementia (5%)

- Visual hallucinations, Parkinson's features

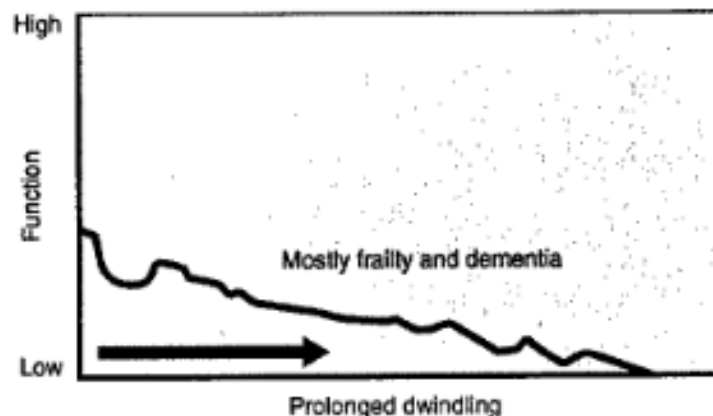
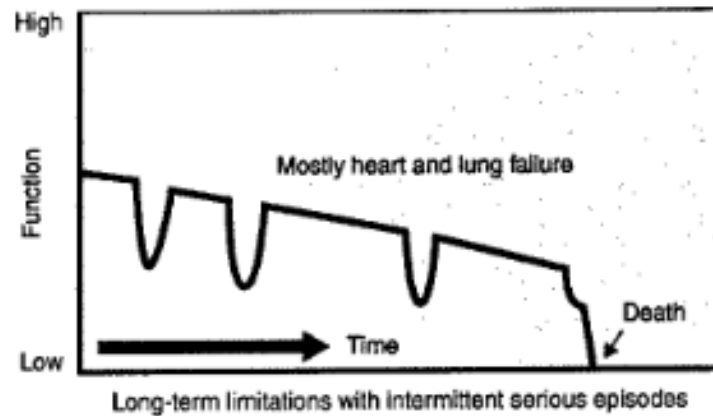
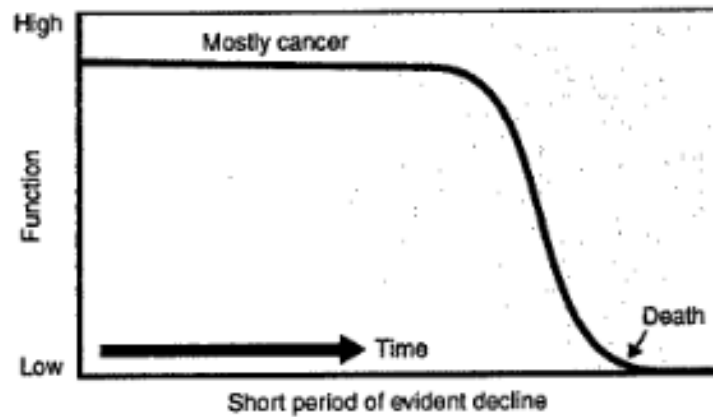
Fronto-temporal Dementia

- Young age, personality change, disinhibition, rapid progression

Reversible causes (1-2%)

- Metabolic d/o, drugs, medications, toxins, liver disease, kidney disease, vitamin B deficiency
- Infections: AIDS, Syphilis, Lyme's disease
- Depression/Pseudodementia

Three Trajectories of Serious Illness



Life expectancy after dementia diagnosis:

- 4-8 years after Alzheimer's diagnosis
- 6-7 years for patients in their 60s
- 1.9 years for patients in their 90s

Lynn, J., & Adamson, D. M. (2003). Living well at the end of life: adapting health care to serious chronic illness in old age. Santa Monica: Rand.

— Lucy's Story:

Decisions for Lucy and Patrick

- Long term care facility, memory care
- Appoint health care proxy
- Prepare a will and financial planning
- Assess driving ability
- Complete advance directives
 - CPR
 - artificial feeding
 - acute care
 - hospitalization



Advance Care Planning (ACP)

ACP involves making decisions about the medical care a person would want to receive in the future, especially in situations where they may not be able to communicate their preferences.

Key components of ACP

1. Discussion of Values and Goals with healthcare providers, family members, and loved ones about patient's values, priorities, and goals for medical care.

2. Healthcare Proxy or Durable Power of Attorney for Health Care: Designating someone who can make medical decisions on a patient's behalf if the patient is unable to do so.

3. Documentation and Legal Forms (e.g., advance directives) provide a way to legally express the patient's wishes regarding medical treatment.

4. Living Will: Documenting preferences for medical treatments and interventions if an individual cannot communicate or make decisions themselves about

- Life-sustaining treatments (e.g., CPR)
- Resuscitation
- Other medical interventions

5. Regular Review and Updates: Preferences for medical care may change over time, so it's important to review and update advance care plans periodically, especially after significant life events or changes in health.

A close-up photograph of an elderly woman's face, focusing on her right eye which is a striking blue color. Her skin is wrinkled and aged, and she has a thoughtful or serious expression. The lighting is soft, highlighting the texture of her skin.

— Lucy's Story continues:

While Lucy still had capacity to make decisions regarding her healthcare, she

1. completed advanced directives with Patrick's help
2. finalized her living will
3. designated Patrick as her healthcare proxy
4. filled out POLST form (Physician Orders for Life-Sustaining Treatment, such as DNR and DNI).

Oklahoma POLST

https://www.okmedicalboard.org/download/819/POLST_09-01-16.pdf

FORM SHALL ACCOMPANY PERSON WHEN TRANSFERRED OR DISCHARGED																	
Oklahoma Physician Orders for Life-Sustaining Treatment (POLST)		Patient's Last Name/First Name/Middle Initial <hr/> Date of Birth: <hr/> Effective Date of this Form: <hr/> Form must be reviewed at least annually.															
This Physician Order set is based on the patient's current medical condition and wishes and is to be reviewed for potential replacement in the case of a substantial change in either, as well as in other cases listed under F. Any section not completed indicates full treatment for that section. Photocopy or fax copy of this form is legal and valid.																	
A. Check One	CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing. <input type="checkbox"/> Attempt Resuscitation (CPR) <input type="checkbox"/> Do Not Attempt Resuscitation (DNR/ no CPR) When not in cardiopulmonary arrest, follow orders in B, C, and D below.																
B. Check One	MEDICAL INTERVENTIONS: Person has pulse and/or is breathing. <input type="checkbox"/> Full Treatment Includes the use of intubation, advanced airway interventions, mechanical ventilation, defibrillation or cardio version as indicated, medical treatment, intravenous fluids, and cardiac monitor as indicated. Transfer to hospital if indicated. Include intensive care. Includes treatment listed under "Limited Interventions" and "Comfort Measures." Treatment Goal: Attempt to preserve life by all medically effective means. <input type="checkbox"/> Limited Interventions Includes the use of medical treatment, oral and intravenous medications, intravenous fluids, cardiac monitoring as indicated, noninvasive bi-level positive airway pressure, a bag valve mask, or other advanced airway interventions. Includes treatment listed under "Comfort Measures." Do not use intubation or mechanical ventilation. Transfer to hospital if indicated. Avoid intensive care. Treatment Goal: Attempt to preserve life by basic medical treatments. <input type="checkbox"/> Comfort Measures only Includes keeping the patient clean, warm, and dry; use of medication by any route; positioning, wound care, and other measures to relieve pain and suffering. Use oxygen, suction, and manual treatment of airway obstruction as needed for comfort. Transfer from current location to intermediate facility only if needed and adequate to meet comfort needs and to hospital only if comfort needs cannot otherwise be met in the patient's current location (e.g., hip fracture; if intravenous route of comfort measures is required). Additional Orders: _____																
C. Check One	ANTIBIOTICS <input type="checkbox"/> Use Antibiotics to preserve life. <input type="checkbox"/> Trial period of antibiotics if and when infection occurs. *Include goals below in E. <input type="checkbox"/> Initially, use antibiotics only to relieve pain and discomfort. +Contact patient or patient's representative for further direction. Additional Orders: _____																
D. Check One in Each Column	ASSISTED NUTRITION AND HYDRATION Administer oral fluids and nutrition, if necessary by spoon feeding, if physically possible. <table border="0" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 33%; vertical-align: top;"> <table border="0" style="width: 100%;"> <tr> <td style="text-align: center;">TPN (Total Parenteral Nutrition- provision of nutrition into blood vessels)</td> <td style="text-align: center;">Tube Feeding</td> <td style="text-align: center;">Intravenous (IV) Fluids for Hydration</td> </tr> <tr> <td><input type="checkbox"/> TPN long-term if needed</td> <td><input type="checkbox"/> Long-term feeding tube if needed</td> <td><input type="checkbox"/> Long-term IV fluids if needed</td> </tr> <tr> <td><input type="checkbox"/> TPN for a trial period*</td> <td><input type="checkbox"/> Feeding tube for a trial period*</td> <td><input type="checkbox"/> IV fluids for a trial period*</td> </tr> <tr> <td><input type="checkbox"/> Initially, no TPN+</td> <td><input type="checkbox"/> Initially, no tube feeding</td> <td><input type="checkbox"/> Initially, no IV fluids+</td> </tr> </table> </td> <td style="width: 33%;"></td> <td style="width: 33%;"></td> </tr> </table> Additional Orders: _____ *Include goals below in E. +Contact patient or patient's representative for further direction.		<table border="0" style="width: 100%;"> <tr> <td style="text-align: center;">TPN (Total Parenteral Nutrition- provision of nutrition into blood vessels)</td> <td style="text-align: center;">Tube Feeding</td> <td style="text-align: center;">Intravenous (IV) Fluids for Hydration</td> </tr> <tr> <td><input type="checkbox"/> TPN long-term if needed</td> <td><input type="checkbox"/> Long-term feeding tube if needed</td> <td><input type="checkbox"/> Long-term IV fluids if needed</td> </tr> <tr> <td><input type="checkbox"/> TPN for a trial period*</td> <td><input type="checkbox"/> Feeding tube for a trial period*</td> <td><input type="checkbox"/> IV fluids for a trial period*</td> </tr> <tr> <td><input type="checkbox"/> Initially, no TPN+</td> <td><input type="checkbox"/> Initially, no tube feeding</td> <td><input type="checkbox"/> Initially, no IV fluids+</td> </tr> </table>	TPN (Total Parenteral Nutrition- provision of nutrition into blood vessels)	Tube Feeding	Intravenous (IV) Fluids for Hydration	<input type="checkbox"/> TPN long-term if needed	<input type="checkbox"/> Long-term feeding tube if needed	<input type="checkbox"/> Long-term IV fluids if needed	<input type="checkbox"/> TPN for a trial period*	<input type="checkbox"/> Feeding tube for a trial period*	<input type="checkbox"/> IV fluids for a trial period*	<input type="checkbox"/> Initially, no TPN+	<input type="checkbox"/> Initially, no tube feeding	<input type="checkbox"/> Initially, no IV fluids+		
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PATIENT PREFERENCES AS A BASIS FOR THIS POLST FORM																	
Patient Goals/Medical Condition:																	
<input type="checkbox"/> The patient has an advance directive for health care in accordance with Sections 3101.4 or 3101.14 of Title 63 of the Oklahoma Statutes. <input type="checkbox"/> The patient has a durable power of attorney for health care decisions in accordance with paragraph 1 of Subsection B of Section 1072.1 of Title 58 of the Oklahoma Statutes. Date of execution: _____ If POLST not being executed by patient: We certify that this POLST is in accordance with the patient's advance directive.																	

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— Lucy's Story continues:

- Five years after the initial diagnosis, Lucy is living in a nursing home.
- She is wheel-chair bound, incontinent of stool and urine, utters a few words a day.
- During the past month, she has required more assistance with feeding and is pocketing food in her mouth.
- She was recently admitted to the hospital for pneumonia.
- She has developed stage-2 sacral pressure ulcer.
- She has lost 15 lbs. in the last 6 months.
- Patrick is concerned about Lucy's eating and wants to discuss feeding options.

Dementia-related care decisions

Nutrition

The American Geriatrics Society recommends that **careful hand feeding** is almost as good as **tube feeding** for the outcomes of comfort, aspiration pneumonia, functional status, and death while, at the same time, **avoiding the burdens and complications associated with tube feeding**.

- Studies show that dementia patients who receive tube feeding have much higher risk of death compared with those receiving oral feeding

Problems with tube feeding

1. **Aspiration pneumonia** remains a significant complication and frequently accounts for the cause of death after tube feeding
2. Dementia patients with PEG feeding were more than twice likely to develop a **new pressure ulcer**.
3. **Refeeding syndrome** characterized by severe electrolyte imbalance and fluid retention that may cause various organs and systems failure, thus contributing to worsening morbidity and high risk of death

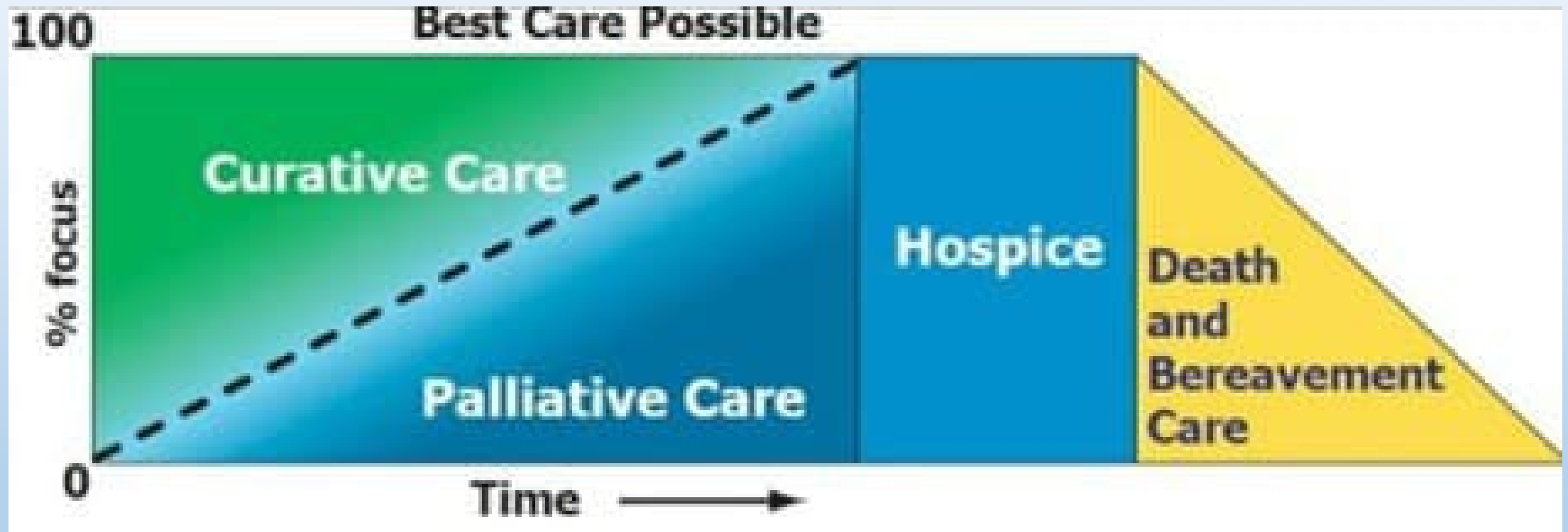
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6942829/>

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— Lucy's Story continues:

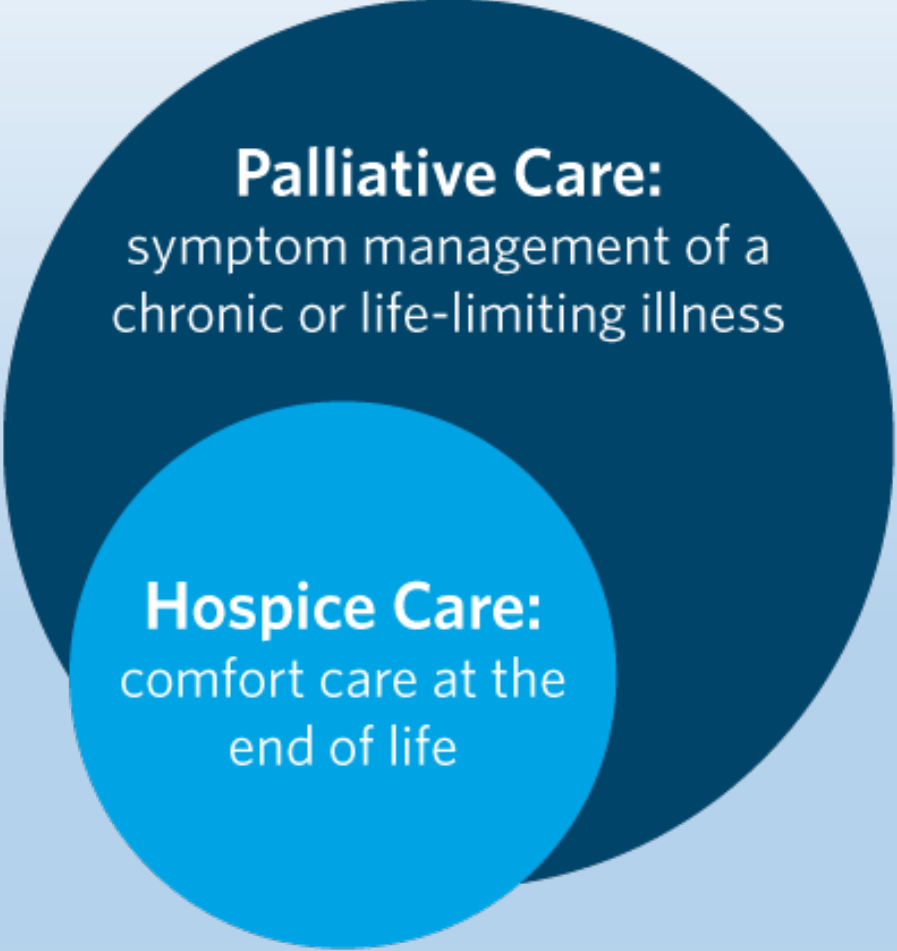
- After discussing with the physician, Patrick decided against tube feeding.
- Lucy now eats with slow hand-feeding, is taking in minimal calories, and continues to lose weight.
- All her medications, including Donepezil, have been discontinued.
- She is now bed-bound and completely dependent in all ADLs.
- She develops occasional periods of restlessness and fevers that respond to acetaminophen.
- After discussion with Patrick, Lucy is enrolled in a hospice program.
- Lucy passed away peacefully in a nursing home 4 months after hospice enrollment.

Curative and Palliative Care



Lynn, J. (2005). Living long in fragile health: the new demographics shape end of life care. *Hastings Center Report*, 35(7), s14-s18.

Hospice Care vs. Palliative Care



Palliative Care:
symptom management of a
chronic or life-limiting illness

The diagram consists of two overlapping circles. The larger, outer circle is dark blue and contains the text for Palliative Care. The smaller, inner circle is a lighter blue and overlaps the bottom-left portion of the larger circle, containing the text for Hospice Care. This visualizes Hospice Care as a specific subset of the broader Palliative Care.

Hospice Care:
comfort care at the
end of life

Hospice Care Eligibility

To be eligible for Medicare hospice benefits, the following criteria must be met:

- Patient eligible for Medicare Part A
- Certification of life-limiting illness and expected death in 6 months or less by PCP and hospital medical director
- Patient agrees to choose hospice care
- Care provided by Medicare approved hospice program

Dementia Hospice Eligibility

- Stage 7 or beyond according to the FAST scale
- Unable to ambulate without assistance
- Unable to dress without assistance
- Unable to bathe without assistance
- Urinary or fecal incontinence, intermittent or constant
- No meaningful verbal communication, stereotypical phrases only, or ability to speak limited to six or fewer intelligible words
- Plus one of the following within the past 12 months:
 - Aspiration pneumonia
 - Pyelonephritis or other upper UTI
 - Septicemia
 - Multiple stage 3 or 4 decubitus ulcers
 - Fever that recurs after antibiotic therapy
 - Inability to maintain sufficient fluid and calorie intake, with 10 percent weight loss during the previous six months or serum albumin level less than 2.5 g per dL (25 g per L)

5

Schonwetter RS, Han B, Small BJ, Martin B, Tope K, Haley WE. Predictors of six-month survival among patients with dementia: an evaluation of hospice Medicare guidelines. *Am J Hosp Palliat Care* 2003;20:105-13.

Functional Assessment Scale (FAST)

1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised.*
6	Occasionally or more frequently over the past weeks. * for the following A) Improperly putting on clothes without assistance or cueing . B) Unable to bathe properly (not able to choose proper water temp) C) Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) D) Urinary incontinence E) Fecal incontinence
7	A) Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. B) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview C) Ambulatory ability is lost (cannot walk without personal assistance.) D) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) E) Loss of ability to smile. F) Loss of ability to hold up head independently.

*Scored primarily on information obtained from a knowledgeable informant. *Psychopharmacology Bulletin*, 1988 24:653-659.

Services Covered Under Medicare Hospice Benefits

Comprehensive interdisciplinary team-based care, that includes

- Physician services
- Nursing care
- Social work services
- Dietary
- Grief support and counselling
- Medical equipment (e.g., wheelchair, walker, hospital bed, etc.)
- Medical supplies (e.g., catheter, bandages, etc.)
- Medications for symptom control
- Short-term care in the hospital, including respite care
- PT/OT, speech therapy

Services NOT Covered Under Medicare Hospice Benefits

- Treatment where goal is curative
- Medications not directed related to hospice diagnosis
- Care from another provider that is not part of the hospice team
- Nursing home room and board

Where is Hospice Care Provided?

- At home
- Long-term care facility
- Inpatient hospice at a free-standing inpatient facility or within a hospital for
 - Management of symptoms like pain, shortness of breath, anxiety, etc.
 - Respite care
 - End of life-care

THANK YOU

Q&A

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