Practical Tips around Palliative Care for People Living with Dementia

Maureen C. Nash, MD, FAPA, FACP
Medical Director, Providence ElderPlace PACE Oregon
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Disclosures

- No financial disclosures

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At the end of this presentation, attendees will be able to

- List 3 things requirements for making a dementia diagnosis
- List 3 tools for person centered care planning in dementia
- Be able to describe a framework for a family meeting about prognosis in those with dementia

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What is palliative care?

The World Health Organization defines palliative care "an approach that improves the quality of life of patients and their families facing the problems 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."

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Palliative Care:

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Dementia is a complex neuropsychiatric disorder.

It can be described as Chronic brain failure.

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What is dementia (aka a degenerative Major Neurocognitive Disorder)?

- A cognitive, behavioral and functional disease
- A life limiting and terminal disease
- A cause of significant suffering

- Most major types including Alzheimer's Disease, Lewy Body Dementia/PDD and Frontal Temporal include **significant verbal communication impairments (of different types)**

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A special note about behavior

- Behavior by those who are living with dementia

- 2 categories:
  - "Behavior Disturbance"
  - Behavior as Communication

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Words & language for those with dementia

- Our brains are hardwired to attend to words
- This can be misleading in an illness that attacks the language centers of the brain
- Alzheimer's Disease and Frontal Temporal Dementias directly involve the parts of the brain used to produce and understand language
- Relying on the language people living with dementia use OR relying on language to communicate to people living with dementia is PROBLEMATIC

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Words & language for those with dementia

- What is the purpose of your language:
  - Content vs relationship?
- Many times the emotion you express is more important than the exact content of the words
- **If there is a mismatch between words and expressed emotions, listen to the emotion**
- **If there is a mismatch between words and actions,**

  listen to the actions

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But what about cognition and various cognitive impairments and assessment of those?

- We advocate use for the actual care planning itself
  - Abilities
  - Deficits
- We advocate against
  - Using for staging of dementia: mild, moderate, severe
  - Using for prognostication

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Cultural Considerations

Points to consider for assessment & care planning:

- Values: collective versus individual
- Relationship and lifestyle choices
- Relationship to medical system
- Family support
- Socioeconomic status
- Personal ideas on independence
- Perspectives on illness and cause

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Examples of tools for person-centered care planning

- Mini Suffering State Exam
- NPI-Q
  - Neuropsychiatric Inventory
- PAINAD
  - Pain in Advanced Dementia

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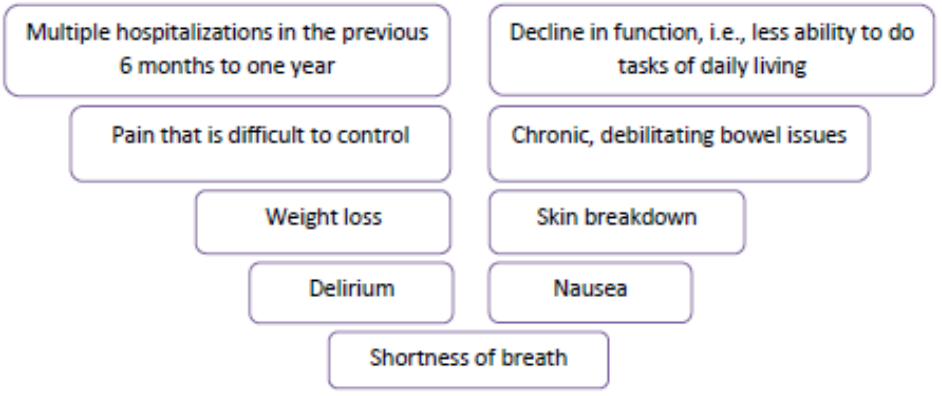
Accurately staging end of life in those with dementia



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Mini Suffering State Examination (MSSE)

A simple tool to measure suffering in those with end stage dementia

Aminoff et al Arch Gerontol Ger 2004; 38: 123-130

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Mini Suffering State Examination

Suffering Item	Explanation	Yes= 1 point
Not calm	1st significant expression without verbal communication	
Screams	Sign of desperation and call for help that indicates suffering	
Pain	Difficult to recognize in end-stage dementia- watch facial expression while percussing, palpating etc.	
Decubitus ulcers		
Malnutrition	Reflected by Total Protein, Albumin, Cholesterol, Hemoglobin …	

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Suffering Item	Explanation	Yes= 1 point
Eating Disorders	Refusal to eat, oropharyngeal dysphagia, anorexia, PEG	
Invasive action	Frequent blood tests, intubation, catheterizations, constant fluid transfusions, hemodialysis, mechanical ventilation, etc.	
Unstable Medical Condition	Acute medical status such as pneumonia, urosepsis, electrolyte imbalance in the last few months	
Suffering (medical opinion)	Suffering is not a diagnosis	
Suffering (family opinion)	Do you believe that your loved one is suffering?	

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MSSE score interpretation

- Low level of suffering 0-3
- Intermediate level of suffering 4-6
- High level of suffering 7-10

- High level of agreement on 7 items

- High level of disagreement on “not calm” and “suffering according to physician’s opinion”

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The MSSE predicts mortality

(Aminoff BZ Adunsky A. Their last 6 months: suffering & survival of end stage dementia pts, 2006; Age and Aging. 597-601)

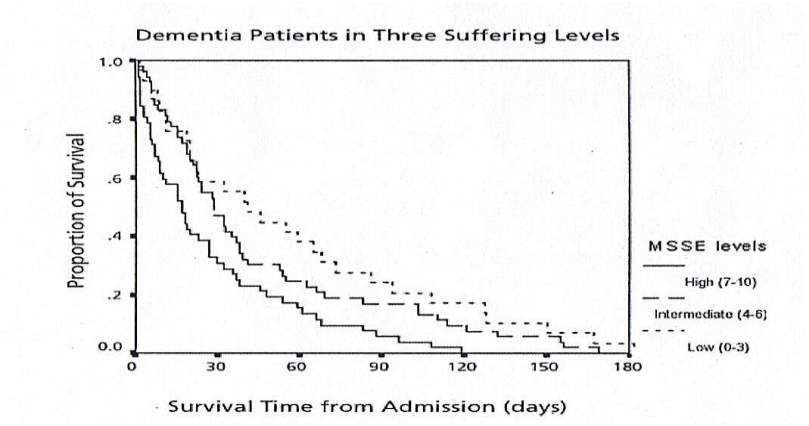

Figure 1. Kaplan–Meier 6-month survival curves for end-stage dementia patients in three suffering levels.

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How do people with dementia die?

- with inadequate pain control
- with feeding tubes in place
- Without the benefits of palliative or hospice care

- Sachs GA, Shega JW, Cox-Hayley D. Barriers to Excellent End-of-life Care for Patients with Dementia. **J Gen Int Med: 19(10)** 1057–1063, 2004

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PAIN – AD scale (developed for dementia)

Items	0	1	2
A) Breathing independent of vocalization	Normal	Occasional labored breathing.	Noisy labored breathing.
B) Negative vocalization	None	Occ. moaning. Speech w/ negative or disapproving quality.	Repeated calling out. Loud moaning or groaning. Crying
C) Facial expression	Smiling or inexpressive	Sad. Frightened. Frowning.	Facial grimacing.
D) Body language	Relaxed	Tense. Distressed. Pacing. Fidget	Rigid. Fists clenched. Pull/push away. Hitting
E) Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.

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NEUROPSYCHIATRIC INVENTORY (NPI)

AMERICAN PSYCHIATRIC ASSOCIATION

Symptom	Anytime during illness	Shown in last month
Delusions	50%	35%
Hallucinations	28	20
Agitation/Aggression	63	52
Depression	54	45
Anxiety	50	44
Apathy	76	75

(Craig et.al, 2005)

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NEUROPSYCHIATRIC INVENTORY (NPI)

AMERICAN PSYCHIATRIC ASSOCIATION

Symptom	Anytime during illness	Shown in last month
Euphoria	17	23
Irritability	63	55
Aberrant Motor Behaviors	65	57
Sleep Disturbance	54	42
Appetite	64	54

(Craig D et al.,2005)

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What is caregiver education?

- Providing direct caregivers with the tools to provide appropriate interventions
- Caregiver Support Groups
  - Research shows it decrease stress and improves quality of life
- Designing and providing stage specific treatment plans
  - Uses current evidence
  - Based on clinical expertise

Cooper et.al. 2012; Kverno et al 2009; O'Neil et al., 2011

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Treatment Planning

- Advanced directives recognizing that dementia is a fatal progressive illness
  - Identify residents goals, discuss realistic details of what the disease entails and where the resident is in the disease trajectory
    - Ex. If a person hopes to die in their sleep, then a pacemaker may not be what they want
- Identify symptoms (use a scale like BEHAVE-AD or Neuropsychiatric Inventory or NPI) etc
- Assess (and document) if resident and/or family believe symptoms are addressed

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Person Centered

- Identify the world in which they live, avoid reality orientation
- **People with dementia cannot change, you can**
- Respect personality, likes, interests
- Retain composure, non reactive responses

Example: 84 year old man with dementia spends the day washing floors with his hands and taking the molding off walls. He says he “has to work”

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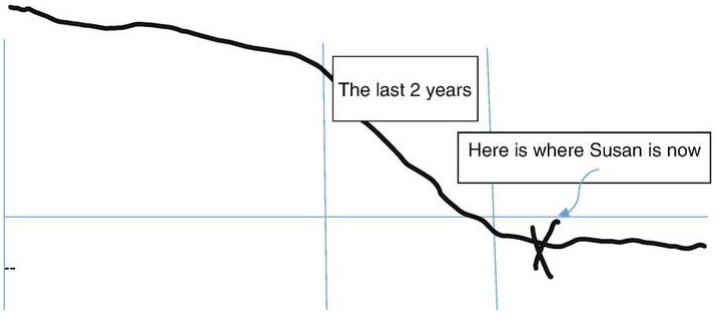
Example for use in a family meeting



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Take Home Message

- Dementia is a progressive, terminal illness
- Consider introducing palliative care at diagnosis
- Discussions need to be honest and open with caregivers
- Treat the person, not the symptom
- Quality of life includes engagement in meaningful activity, connection with caregivers, interpreting behaviors as communication, controlling pain

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Palliative Care for Dementia Toolkit: Oregon Partnership to Improve Dementia Care

https://www.oregon.gov/DHS/PROVIDERS-PARTNERS/LICENSING/CBC/Documents/Palliative-Care-Toolkit.pdf

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Contact: Maureen.Nash@providence.org

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The Supportive Care Coalition is excited to announce its integration with the Catholic Health Association in January 2021!

For more information starting in 2021 go to
https://www.chausa.org/palliative/palliative-care

Supportive Care COALITION
Advancing Excellence in Palliative Care

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