



How Palliative Care Eases the Burden of Dementia

Deanna Speer MSN, RN, CHPN
Leslie Hale, LMSW



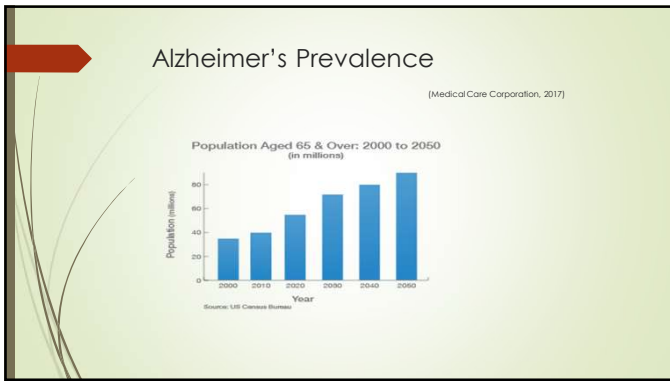
Objectives

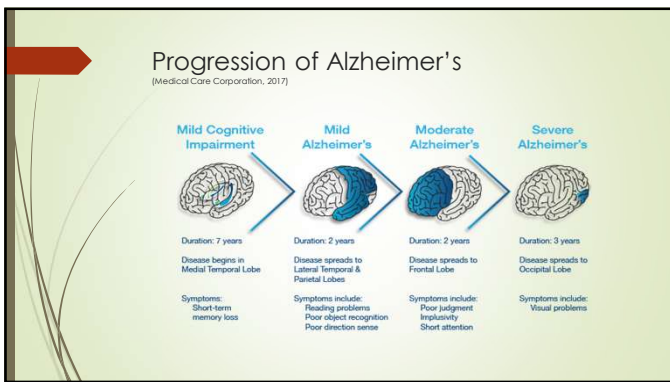
- Identify the 7 stages and progression of dementia
- Explain the benefit of palliative care to patients and families dealing with dementia
- Explain the importance of advance care planning in the care of persons with dementia
- Discuss the components of the Kansas Alzheimer's Disease Plan that coincide with palliative care initiatives



Alzheimer's (Dementia) Facts

- 4 types of dementia:
 - Alzheimer's disease
 - Vascular dementia
 - Unspecified dementia
 - Other degenerative diseases of the nervous system
- Alzheimer's disease is 1 of 5 leading causes of death in persons ≥ 65
- If you reach 70, your lifetime risk for dementia: 30.8% (male), 37.4% (female)
- Characterized by progressive & nonreversible loss of function, memory, and cognition skills
- Advanced dementia is considered terminal





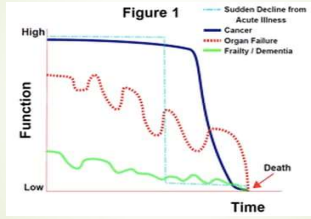
Stages of Dementia

Adapted from Functional Assessment Staging Test (FAST) and Global Deterioration/Reisberg Scale

STAGE	COGNITIVE DECLINE	FUNCTIONAL DECLINE	EXPECTED DURATION
1 No dementia Normal adult	No memory loss Mentally healthy	No functional decline	N/A
2 No dementia Normal older adult	Normal forgetfulness associated with aging	Personal awareness of some functional decline	Unknown
3 Early Dementia or Alzheimer's	Increased forgetfulness; some difficulty concentrating; finding right words; family notices cognitive decline	Noticeable deficits in demanding job situations	Average 7 years
4 Mild Dementia or Alzheimer's	Difficulty concentrating, managing finances, or traveling alone to new locations; decreased memory of recent events; trouble completing complex tasks; may be in denial about symptoms; start withdrawing/difficult socialization	Requires assistance in complicated tasks	Average 2 years
5 Moderate Dementia or Alzheimer's	Major memory deficits; May not remember address/phone no., time of day, where they are	Requires assistance with some ADL, choosing proper clothing	Average 1.5 years
6 Moderate-severe Dementia or Alzheimer's	Start to forget names of close family members; may remember some details of earlier life; ability to speak declines; personality/behavioral changes (delusions, compulsions, anxiety, agitation)	Need extensive assistance with ADL, toileting, urinary and fecal incontinence	Average 3.5 to 9.5 months
7 Severe Dementia or Alzheimer's	Speech ability declines to about 6 intelligible words	Progressive loss of ability to walk, sit up, smile, and hold head up	Average 1 to 1.5 years

Illness Trajectory of Dementia

(Comstock Barker MD & Scherer MD, n.d.)



What are the burdens associated with dementia?




- Physical symptoms
- Sensory symptoms
- Psychiatric symptoms
- Financial stress
- Caregiver strain
- Medical treatments

Palliative Care

- Patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care **throughout the continuum of illness** involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

National Consensus Project for Quality Palliative Care



What Matters to Persons with Dementia as they near end of life?

- Cognitive ability
- Physical ability
- Independence
- Comfort
- Sanctity of life
- Acceptance of death



The Benefits of Palliative Care

- Anticipation of and assistance with care planning as the disease progresses
- Helping with the conversations to elicit personal preferences and goals of care
- Expertise in alleviation of pain and other symptoms
- Emotional and spiritual support
- Caregiver support and connection with resources
- Support in the critical decisions during the end stages of the disease



Risks in late-stage dementia

- Dysphagia
- Infection
- Falls/fractures
- Pressure ulcers

© 2011 & Revision, 2012

Realities of Dealing with Decision-Making at the End Stages of Dementia

- Most persons with dementia cannot participate in making decisions due to loss of cognitive and executive functioning
- Most often the health care proxies (DPOA, family members) are called upon to be substituted decision makers
- The challenge often is making emotionally intense decisions that involve a trade-off between quantity and quality of life
- Understanding of the PWD's values is a prerequisite for making end-of-life decisions that match their wishes
- The decision maker needs clear information about the risks and benefits of treatment options and potential outcomes

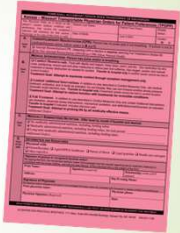
Having the Conversation

- Find out who your loved one wants to make medical decisions for them when not able to do so (medical power of attorney).
- Find out "what matters most" to your loved one (use the Conversation Project Starter Kit).
- Have the conversation as early as possible.
- Have it in small bites and keep it simple.
- Having the conversation lets your loved one know you will be there for them.
- Remember you are speaking for your loved one – not for yourself.

TPOPP Form

- Section A: Resuscitation Status**
 - For Full Blown cardiac arrest
 - Attempt Resuscitation
 - Do Not Attempt Resuscitation
- Section B: Medical Intervention**
 - Still with pulse and breathing but with rapid health deterioration
 - Comfort Measures Only
 - Limited Additional Interventions
 - Full Treatment
- Section C: Medically Administered Nutrition**
- Section D: Signatures**

This document moves with the patient across health care continuum



Making your wishes known



- "So that you may know 'what Mom wanted,' here are some of my thoughts: When there is no potential for recovery...when I am no longer aware of what is going on about me and able to relate to it...unable to communicate, I don't want extraordinary measures to prolong biological 'life.' It wouldn't be life for me to not be able to feel your touch, know your voice and smile. When I cannot eat and drink or breathe on my own, please no feeding tubes - ventilators. I ask that you would communicate that when it isn't possible for me to do so. I don't want to financially impoverish you in any way. I wouldn't want you to feel guilt for carrying out my wishes, but I would hope you would feel gratitude for our wonderful times together and let me go...."

Sources:

- Advisory Board. (2018, January 30). Advance directives do a terrible job of handling dementia, experts say. How can we do better? Retrieved from Today's Daily Briefing.
- Advisory Board. (2019, March 15). Dementia deaths have tripled since 2000. Retrieved from Today's Daily Briefing.
- Amjad, H., Snyder, S., Wolff, J., Oh, E., & Samus, Q. (2019). Before Hospice: Symptom Burden, Dementia, and Social Participation in the Last Year of Life. *Journal of Palliative Medicine*, *XX*(XX), 1-9.
- Chen, P.-R. H. J., Tien, L.-C., Lu, C.-L., Lin, Y.-P., Chang, H.-P., & Jao, Y.-C. (2019). Perceptions of Reducing Tube Feeding for Persons with Advanced Dementia Among Various Professions in a Teaching Hospital. *Journal of Palliative Medicine*, *23*(16), 300-316.
- Comstock-Baker MD, P., & Scheer MD, J. S. (n.d.). *Illness Trajectories: Description and Clinical Use*. Retrieved August 29, 2019, from Palliative Care Network of Wisconsin: <https://www.mypcnw.org/fact-fact/illness-trajectories-description-and-clinical-use/>
- Gallagher, M., & Long, C. (2011, March/April). Advanced Dementia Care. *Journal of Hospice & Palliative Nursing*, *13*(2), 70-78.
- Heath, M., & Nazarian, M. A. (2010, July/August). Palliative Care Can Help Reduce Incidence of Medicare's Never-Events for Dementia Patients. *Journal of Hospice and Palliative Nursing*, *12*(4), 247-254.
- Kwak, J., & Noh, H. (2018, October). What Matters to Persons with Dementia at the End of Life. *Journal of Hospice & Palliative Nursing*, *20*(5), 438-440.
- Lopez, R. P., Mitchell, S., & Givens, J. (2017). Preventing Burdensome Transfers of Nursing Home Residents with Advanced Dementia: It's More than Advance Directives. *Journal of Palliative Medicine*, *20*(11), 1225-1229.
- Medical Care Corporation. (2017). *Alzheimer's Overview*. Retrieved from <http://www.mcccare.com/education/dayreview.html>
- Palliative Care Network of Wisconsin. (2018). *Prognostication in Dementia*. Retrieved from *Fact Facts in Palliative Care*: <https://www.mypcnw.org/fact-fact/prognostication-in-dementia/>
- Palliative Care Network of Wisconsin. (2019). *Swallow Studies, Tube Feedings, and the Death Spiral*. Retrieved from *Palliative Care Fact Facts*: <https://www.mypcnw.org/fact-fact/swallow-studies-tube-feedings-and-the-death-spiral/>
- Pankaj, J. A., & Volcker, L. (2002, July-September). Caring for Persons with Dementia: a Palliative Approach. *Journal of Hospice and Palliative Nursing*, *4*(3), 143-149.
- Smith, L., Arevalo, E., Edmund, B., & Mueller, M. (2014, July). A Dimensional Analysis of the Concept of Suffering in People With Dementia at End of Life. *Journal of Hospice & Palliative Nursing*, *14*(5), 263-270.
- The Conversation Project & the Institute for Healthcare Improvement. (n.d.). *Your Conversation Starter Kit*. Retrieved October 2019, from <https://theconversationproject.org>

2019 Kansas Alzheimer's Disease Plan

- In June 2018, Governor Jeff Colyer, MD created Executive Order 18-14 establishing the State of Kansas Alzheimer's Disease Working Group.
- The workgroup was made up of 21 individuals from various backgrounds such as health care, law enforcement, universities, legislature, caregivers and faith community.
- The time limited workgroup met from August 2018 to November 2018

The Goal of the workgroup was


- Assess the current and future impact of Alzheimer's Disease on residents of the state of Kansas
- Examine the existing industries, services and resources addressing the needs of persons with Alzheimer's their families and caregivers and
- Develop a strategy to mobilize a state response to this public health crisis

Recommendations from the Workgroup

- The workgroup came up with several recommendations in the following categories:
 - Caregivers Support
 - Diagnosis and treatment of Alzheimer's
 - Education and training
 - Law enforcement and first responders
 - Public awareness
 - Research
 - Legal issues
 - Funding
 - Quality assurance
- Additional information on the workgroup and access to the state plan can be found: <https://www.kdads.ks.gov/commissions/commission-on-going/alzheimers-disease-plan-working-group>


Kansas Palliative Care and Quality of Life Interdisciplinary Council

- In 2018, the Kansas Governor signed Senate Sub for House Bill 2031 Quality of Life Interdisciplinary Advisory Council as well as the State Palliative Care Consumer and Professional Information and Education Program.
- HB 2031 became law July 1, 2018
- K.S.A. 65-1260 and K.S.A. 65-1261



Kansas Palliative Care and Quality of Life Interdisciplinary Council


- Make recommendations to KDHE on the establishment, maintenance, operation, outcomes, of palliative care initiatives in the state and the effectiveness of our program.
- Maximize effectiveness of palliative care initiatives across the state.
- Ensure comprehensive and accurate information and education about palliative care is available to all Kansans.



Top Three Priorities for Palliative Care in Kansas

KPC-QOL Council identified 3 top priorities for addressing palliative care in Kansas:

- Access to Palliative Care
- Community/Public Awareness
- Workforce and Education Training



Collaboration of the Palliative Care Advisory Council and Alzheimer's Work Group

- One of the primary recommendations of the 2018 workgroup was to create a Alzheimer's Disease Advisory Council to monitor and help implement the workgroup's recommendations.
- It is very important that the Palliative Care Advisory Council collaborate with the Alzheimer's Association and other Alzheimer's stakeholders to help foster the understanding and utilization of palliative care for individuals living with Alzheimer's disease and their families.



Contact Information

Leslie Hale, LMSW
Palliative Care Program Manager
Division of Public Health
Bureau of Health Promotion
Kansas Department of Health and Environment
Curtis State Office Building
1000 SW Jackson St., Suite 230
Topeka, KS 66612-1368

(785) 296-5535

Leslie.Hale@ks.gov
