PROJECT ECHO MINISERIES:

BEST PRACTICES IN DEMENTIA CARE

Hosted in collaboration with the

Alzheimer's Association

Seven weekly sessions

Thursday, 3 – 4 p.m. ET | March 7 – April 18

nhpco.org/projectecho

NHPCO

Session 1 : Alzheimer's Disease and Dementia in Hospice and Palliative Care

March 7, 2024

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Disclosures

Disclosure

The faculty and planners for this educational event have no relevant financial relationship(s) with ineligible companies to disclose.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

Please complete program evaluation materials following each session.

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

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Today’s Agenda

- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

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Project ECHO Team

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Dementia Care Practice Recommendations (DCPR)

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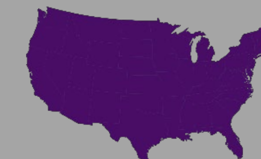
Determinants and Distribution of Dementia

Alzheimer's disease is the leading cause of dementia



More than **6 million** Americans living with Alzheimer's dementia

Percentage of people with Alzheimer's dementia **increases with age**

One in 3 seniors dies with Alzheimer's or another dementia. Deaths from Alzheimer's have increased 145% between 2000-2019)

About 1 in 9 people (10.7%) ages 65 and older has Alzheimer's dementia

People **younger than age 65** can develop Alzheimer's, but it is much less common

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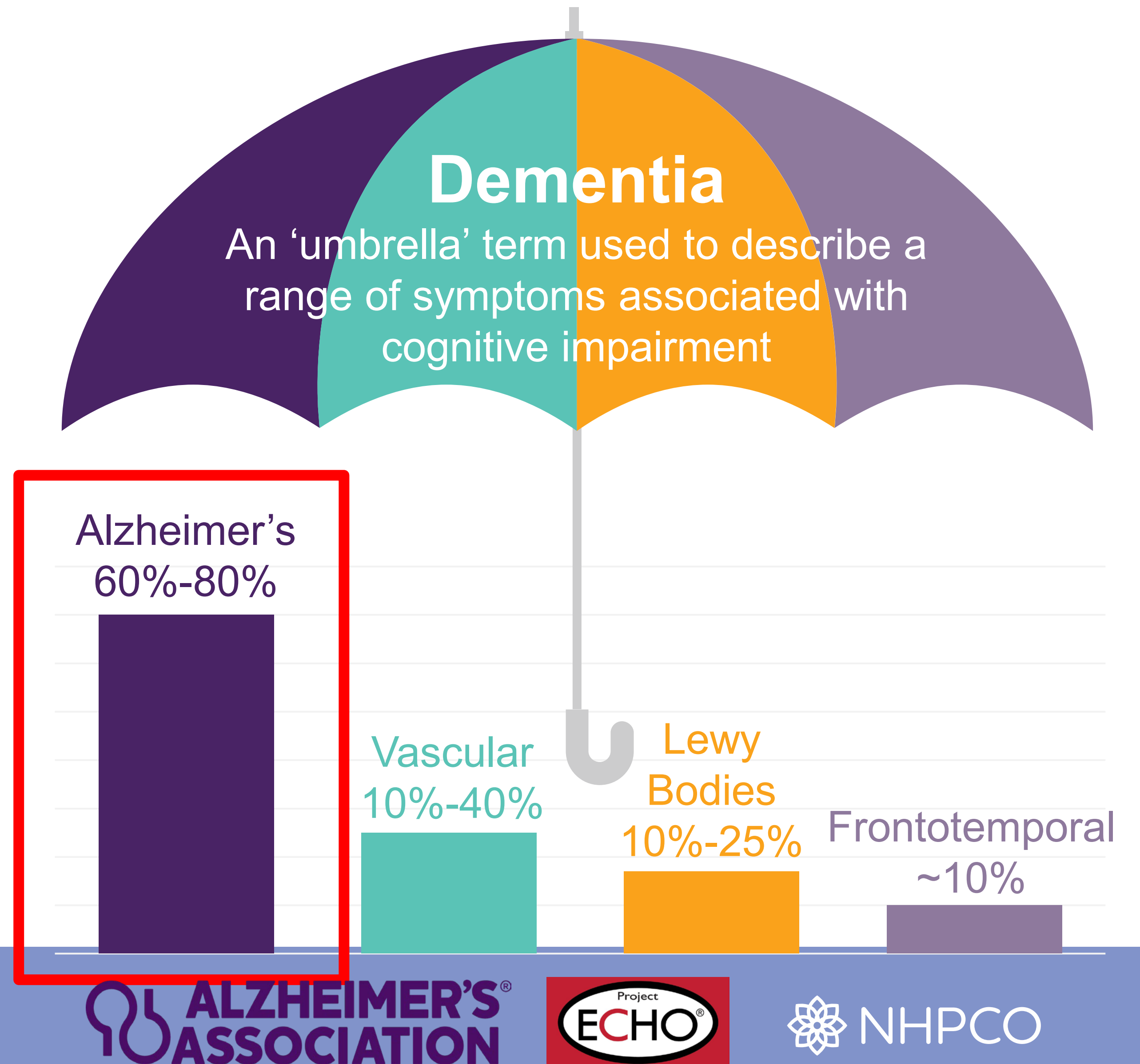
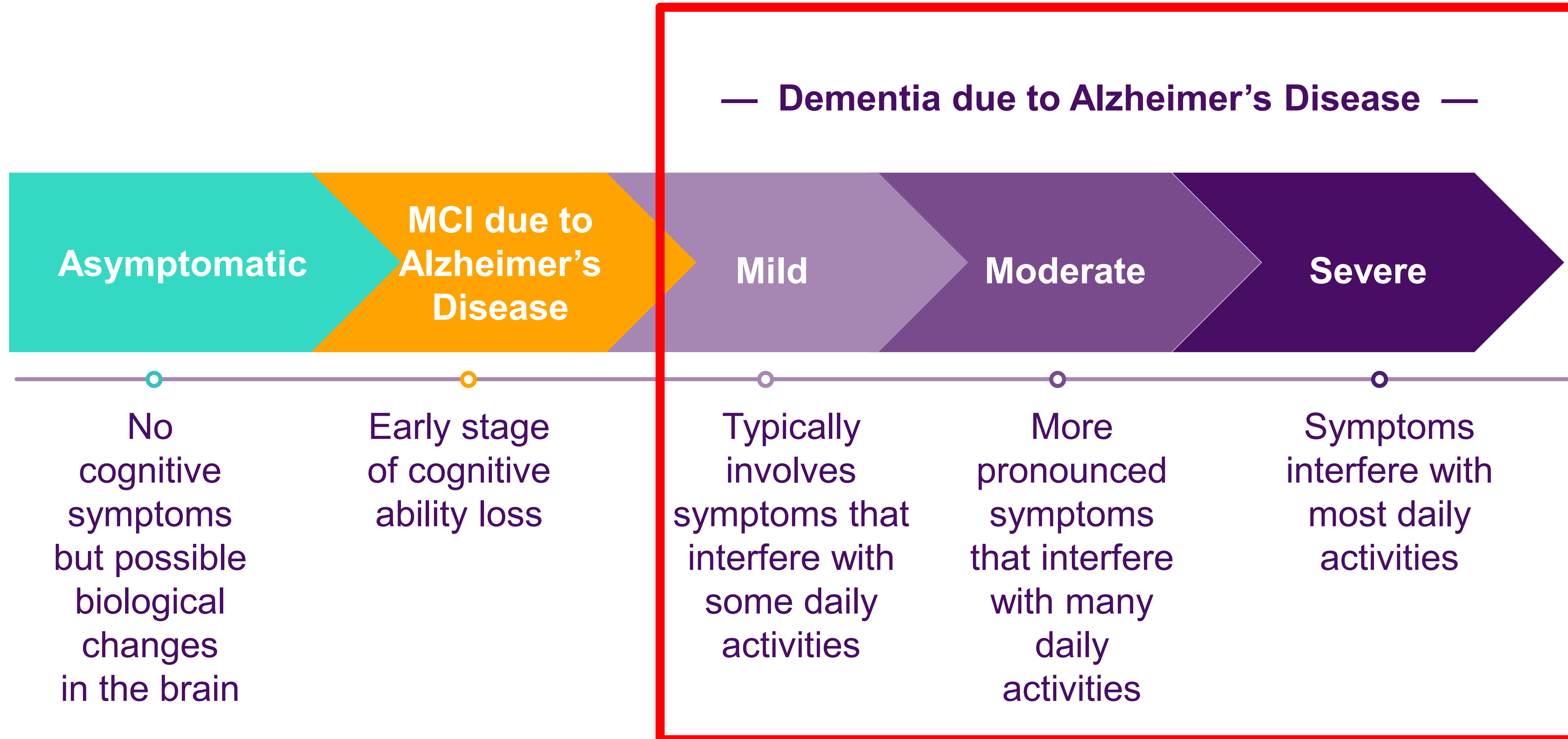
2022 Alzheimer's disease facts and figures. Alzheimers Dement; 18: 30

Dementia is a Syndrome

- Dementia is a collection of symptoms related to cognitive decline
- Can include cognitive, behavioral and psychological symptoms
- Due to biological changes in the brain
- Alzheimer's is most common cause
- Mixed dementia is very prevalent
- Some causes of cognitive decline are reversible and not truly dementia



Alzheimer's Disease Continuum



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State of Disease in Long-Term Care*

- **Almost 60%** of older adults with Alzheimer's or other dementias reside in the community and of those only 25% live alone.
- As their disease progresses, people with Alzheimer's or other dementias generally receive more care from family members, unpaid caregivers, and community-based and residential care providers.
- **Forty-two percent of residents in assisted living communities** (48% NH) have Alzheimer's or other dementias (Caffrey et al., 2012; Zimmerman, Sloane, & Reed, 2014)
- By age 80, **75% of people with Alzheimer's dementia are admitted to a nursing home**, compared with only 4% of the general population (Arrighi, Neumann, Lieberburg, & Townsend, 2010). nd Medicaid Services, 2016).

*Gerontologist (Alzheimer's Association Dementia Care Practice Recommendations), 2018, Vol. 58, No. S1, S1–S9

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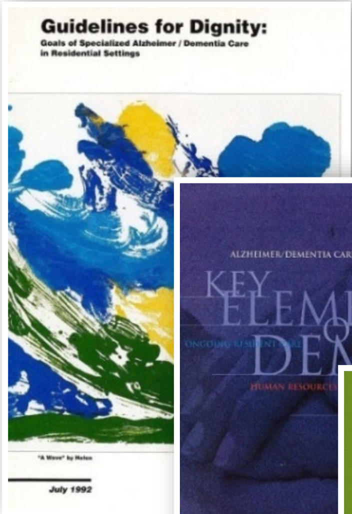
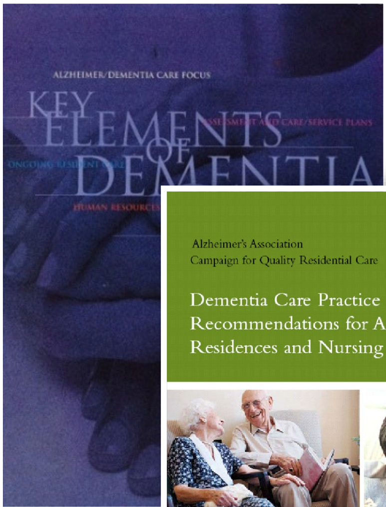
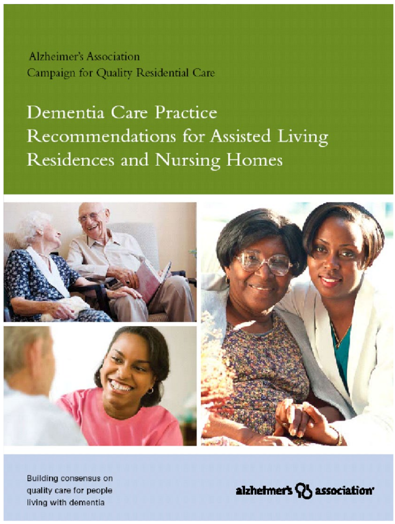
Quality Care History and Today



Guidelines for Dignity



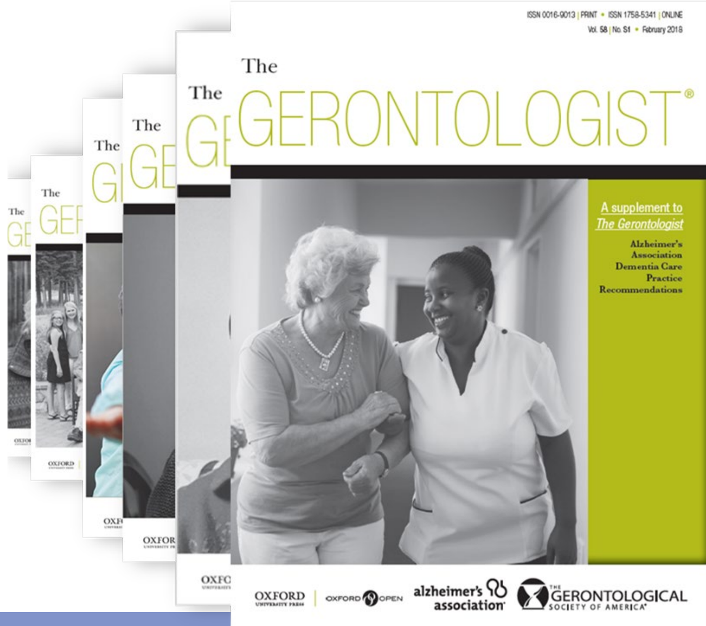
Key Elements of Dementia Care



Dementia Care Practice Recommendations

Latest Version of Dementia Care Practice Recommendations (2018)

- 56 evidence-based recommendations across 10 content areas
- Applicable to various care settings across disease continuum
- Foundation for quality person-centered care

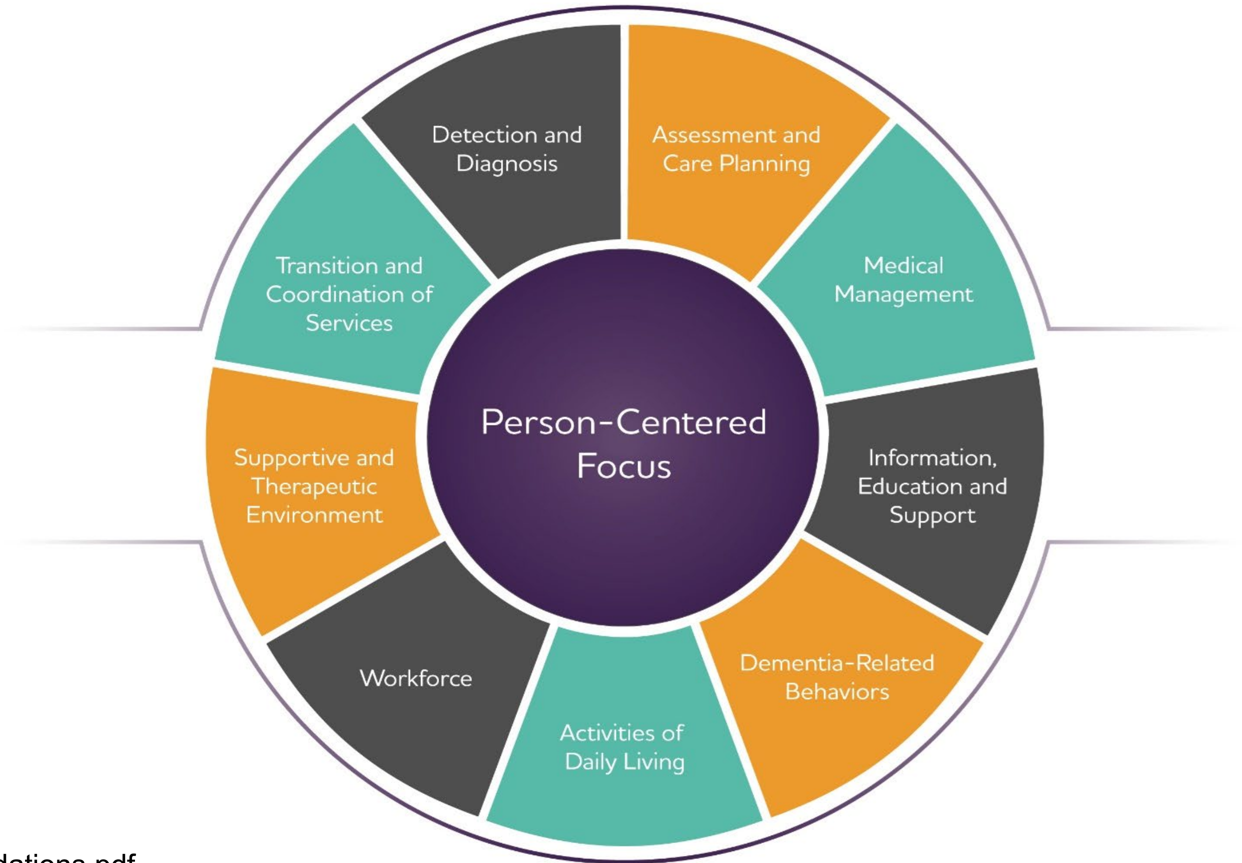


DCPR Foundation

Person-centered care is essential to good dementia care and the underlying philosophy of the 2018 Alzheimer's Association's Dementia Care Practice Recommendations.

Person-centered care:

- Is built around the needs of the individual and contingent upon *knowing the person* through an interpersonal relationship.
- Challenges the traditional medical model of care that tends to focus on processes, schedules, and staff and organizational needs.
- Requires commitment from everyone within the organization, especially leadership



https://www.alz.org/media/Documents/alzheimers-dementia-care-practice-recommendations.pdf

Person-Centered Focus

Dementia Care Practice Recommendations

- Know the person living with dementia
- Recognize and accept the person's reality
- Identify and support ongoing opportunities for meaningful engagement
- Build and nurture authentic, caring relationships
- Create and maintain a supportive community for individuals, families, and staff
- Evaluate care practices regularly and make appropriate changes

Dementia in Palliative Care & Hospice

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VITAS Individualized Pampering (VIP) Program

- Program for residents in senior living communities receiving hospice services to reduce stress, promote engagement, and elevate their care experience
- Spa-like services and memory-support activities incorporated into a resident's individual hospice plan of care
- Performed by VITAS care team with a focus on comfort, relaxation, and support

Items and activities that may be offered include*

- Nail care
- Facial care
- Lavender touch lotion
- Music
- Adult coloring books
- 35-piece puzzles
- Word search puzzles
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VITAS Individualized Pampering (VIP) Program (cont.)

- Clinicians complete a questionnaire for each resident to determine which VIP activities the resident may benefit from:
  - What are some of your hobbies and/ or interests?
  - Is there a particular type of music that you find soothing?
  - What is your career history?
  - Are you a veteran?
  - Do you have any requests for items or activities that may relieve stress or anxiety for you?
- All items or activities are individualized and incorporated into a resident's care plan

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5. What are some of the common careers that your residents had prior to being admitted to your facility?
6. Do you have many residents who are Veterans?

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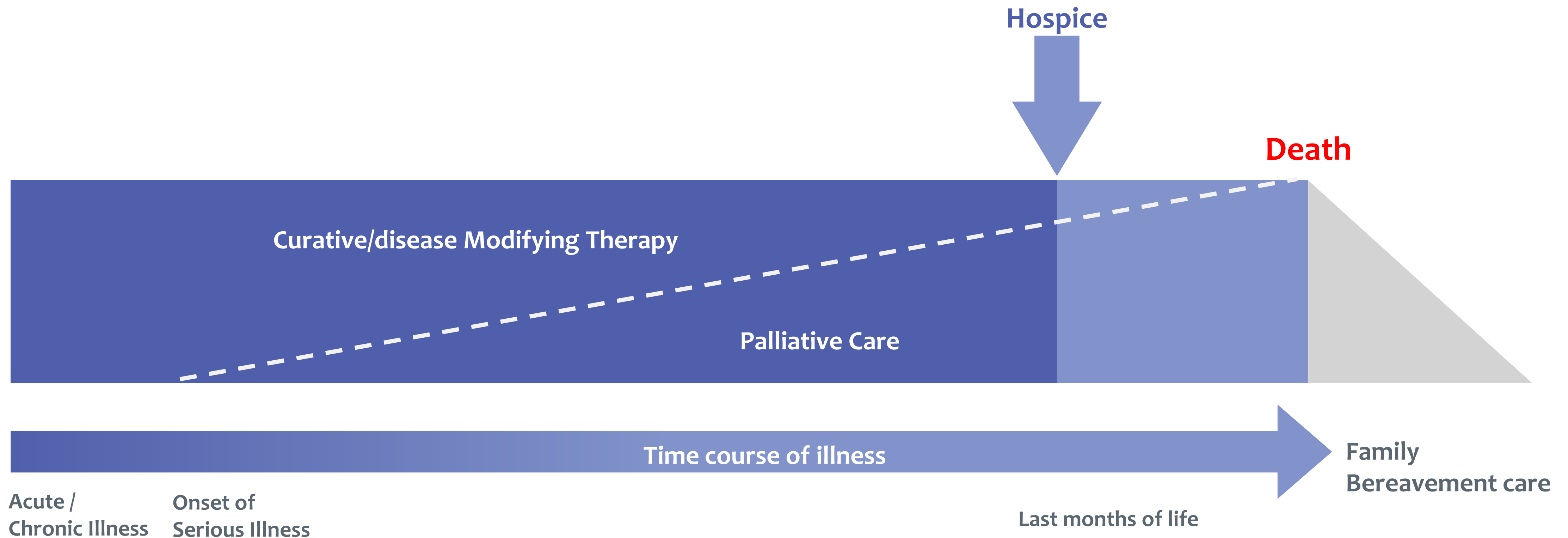
Overview of Palliative Care & Hospice



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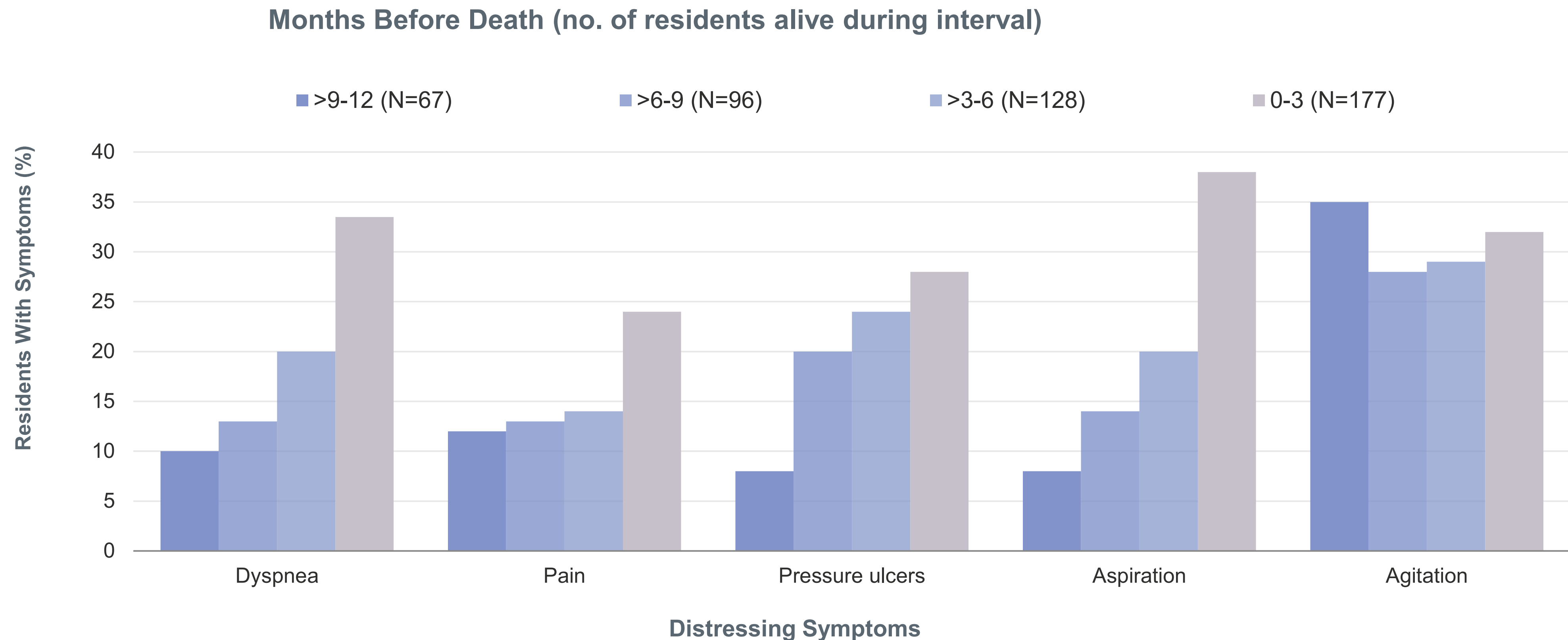
Symptom Experience in Persons With Dementia in the Last Year of Life



Mitchell, et al. (2009). The clinical course of advanced dementia. *New England Journal of Medicine,* (361), 1529-1538.

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Table 2: FY 2022 Top 20 Principal Hospice Diagnoses, by ICD-10 code

Rank	"International Classification of Diseases, Tenth Revision (ICD-10)/Reported Principal Diagnosis"	Number of Beneficiaries	Percentage of all Reported Principal Diagnoses
1	G30.9-Alzheimer disease, unspecified	135,910	7.4%
2	G31.1-Senile degeneration of brain, not elsewhere classified	124,365	6.8%
3	J44.9-Chronic obstructive pulmonary disease, unspecified	78,630	4.3%
4	G30.1-Alzheimer disease with late onset	63,980	3.5%
5	I50.9-Heart failure, unspecified	52,375	2.8%
6	G20-Parkinson disease	52,155	2.8%
7	"I25.10-Atherosclerotic heart disease of native coronary artery withoutangina pectoris"	47,117	2.6%
8	"C34.90-Malignant neoplasm of unspecified part of unspecified bronchus or lung"	44,093	2.4%
9	U07.1-Emergency use of U07.1	43,505	2.4%
10	I67.2-Cerebral atherosclerosis	38,543	2.1%
11	I11.0-Hypertensive heart disease with (congestive) heart failure	36,860	2.0%
12	I67.9-Cerebrovascular disease, unspecified	35,120	1.9%
13	E43-Unspecified severe protein-energy malnutrition	33,111	1.8%
14	I63.9-Cerebral infarction, unspecified	29,291	1.6%
15	"I13.0-Hypertensive heart and renal disease with (congestive) heart failure"	27,455	1.5%
16	C61-Malignant neoplasm of prostate	24,806	1.3%
17	N18.6-End stage renal disease	24,565	1.3%
18	J96.01-Acute respiratory failure with hypoxia	23,329	1.3%
19	C25.9-Malignant neoplasm: Pancreas, unspecified	22,128	1.2%
20	"J44.1-Chronic obstructive pulmonary disease with acute exacerbation, unspecified"	20,928	1.1%

Source: *FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 2*

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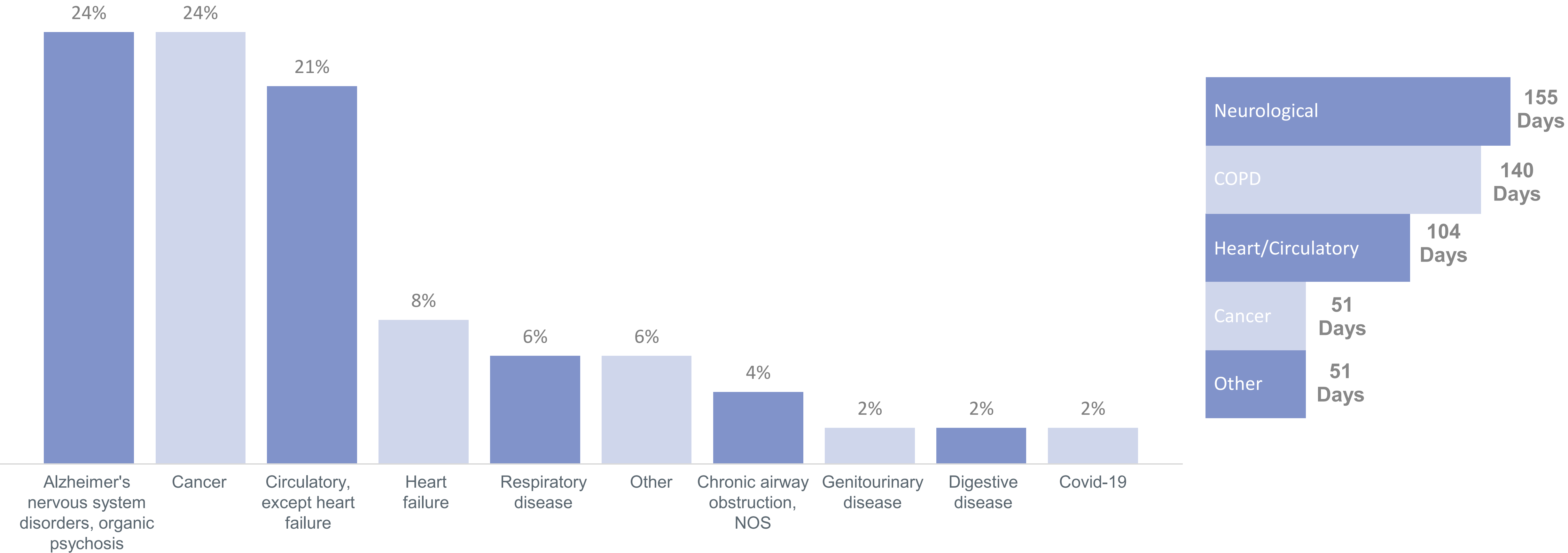
Diagnosis Breakdown and Length of Stay



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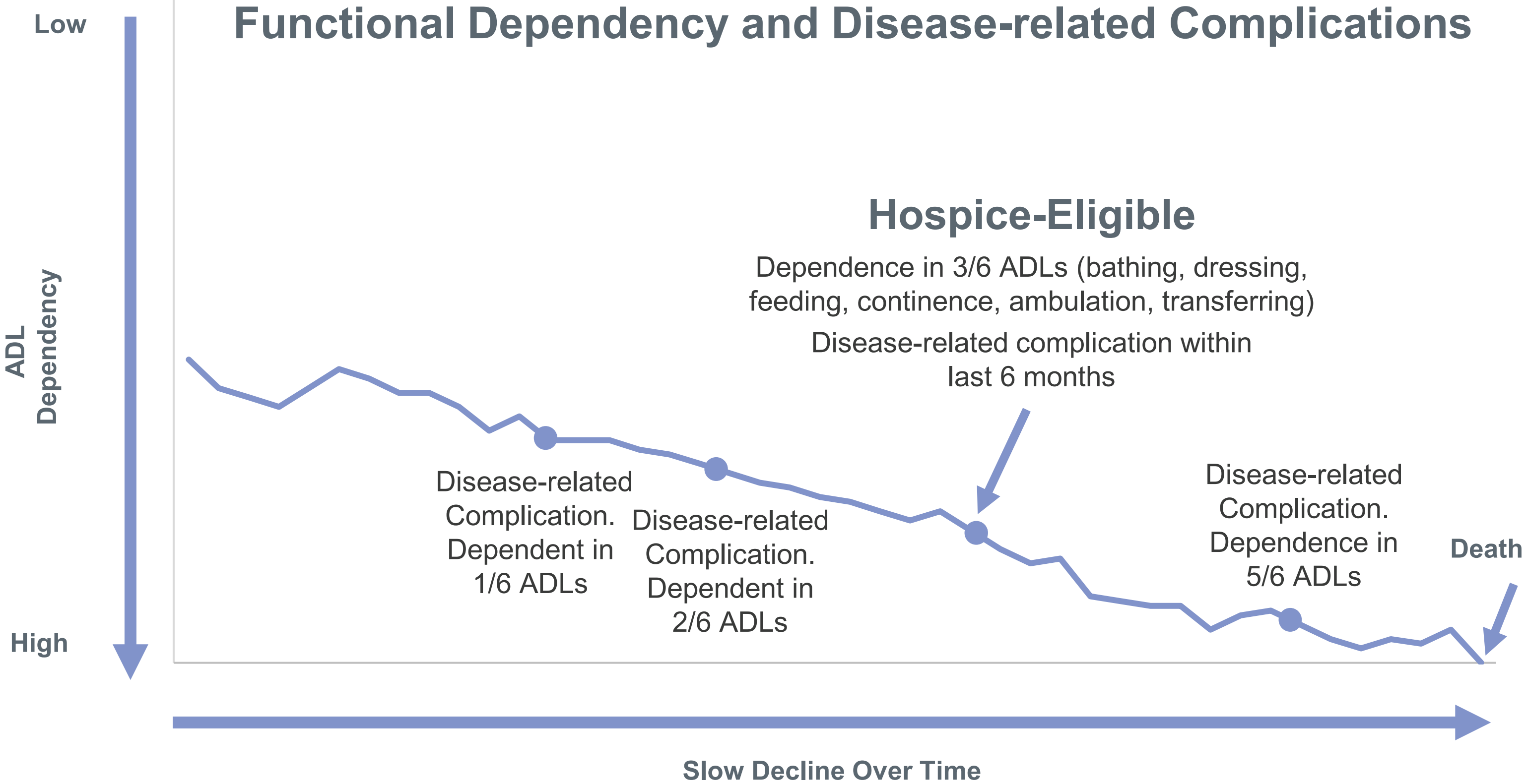
Dementia Natural History



Disease-related complications include, but are not limited to:

- UTI
- Sepsis
- Febrile episode
- Delirium
- Pneumonia
- Hip fracture
- Difficulty eating or dysphagia
- Dehydration
- Feeding tube (decision)

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Dementia Hospice Eligibility Guidelines

Alzheimer's Disease
Lose ability to speak or communicate meaningfully (FAST 7A)

Non-Alzheimer's Disease or Mixed Dementia
Dependent in 3/6 ADLS:
Dress • Incontinence of bowel and bladder
Transferring • Ambulation • Eating • Bathing

Plus have either

A comorbidity resulting in structural/functional impairment:

- Heart Disease (e.g., Heart Failure, Advanced Cardiac Disease, etc.)
- Advanced Lung Disease (COPD)

Or

A clinical complication indicative of disease progression:

- Febrile episode
- Infection requiring antibiotics (aspiration pneumonia, UTI, sepsis)
- Pressure ulcers
- Dehydration requiring hospitalization
- Weight loss 10%
- Eating difficulty including dysphagia
- Delirium
- Feeding tube decision

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Hospice Impact Dementia Care: Patient

- More likely to die at home (76% vs. 38%)
- Less likely to die in the hospital (7% vs. 45%)
- Improved pain and symptom management
- Fewer end-of-life transitions

No hospice last month of life
Hospice last month of life

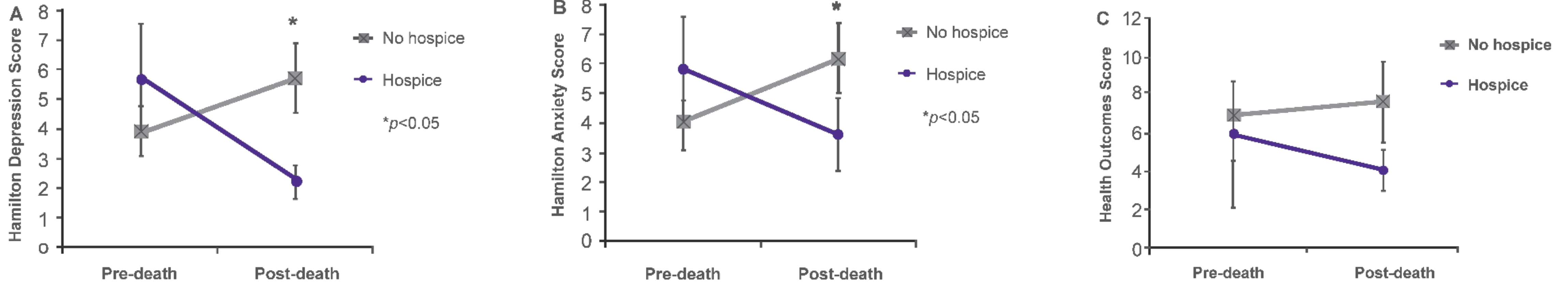
0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Excellent quality of care
Pain needs managed
Breathing managed
Anxiety of sadness managed
Personal care needs always managed
Enough spiritual support
Goal-consistent care
Always treated with respect
Patient or family input
Family always informed
Care coordinated
Late (3 day) transition

Predicted probability

Shega, J., et al. (2008). Patients Dying with Dementia: Experience at the End of Life and Impact of Hospice Care. Journal
Pain and Symptom Management, 35(5), 499-507.
Harrison, K. et al. (2022). Hospice Improves Care Quality For Older Adults With Dementia In Their Last Month Of Life: Stud
examines hospice care quality for older adults with dementia in their last month of life. Health Affairs, 41(6), 821-830.

Hospice Impact Dementia Care: Family



- Increased satisfaction with care
- Decreased burden
- Decreased anxiety and depression
- Improved overall health

Irwin, S., et al. (2013). Association Between Hospice Care and Psychological Outcomes in Alzheimer's Spousal Caregivers. Journal of Palliative Medicine, 16(11), 1450-1454.

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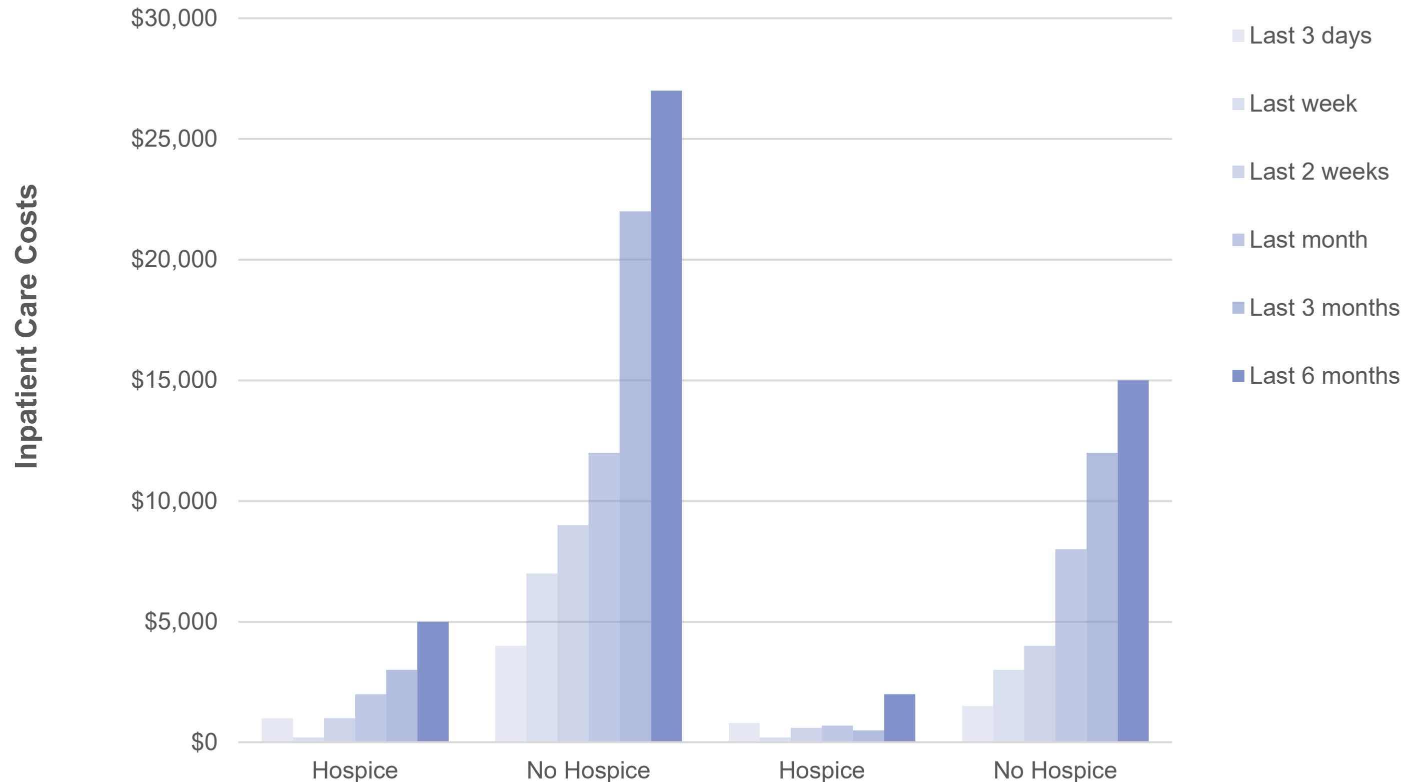
Hospice Impact Dementia Care: Healthcare Utilization



Study Findings

- Hospice improves end-of-life outcomes and reduces burdensome transitions for dementia patients.
- Hospice significantly enhances quality of life for those with dementia in the final year, emphasizing the need for accessible hospice care.
- Hospice services reduce Medicare costs for dementia patients by averting costly inpatient care at the end of life.
- Patients using hospice for three to six months before death save over $8,000 each.

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Didactic Presentation Q&A

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Case Study: M.W.

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Situation

Case Study: MW is a Resident in a Long-Term Care Facility

MW is a 95-year-old female with terminal dx of cerebral atherosclerosis. She is bedbound and unable to complete any task without assistance.

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During visits with your VITAS care team, you can request comforting spa-like services, engaging games, and anxiety-relieving sensory tools that add an extra layer of soothing support for your loved one. The VIP Program services and activities will then be incorporated into their hospice plan of care.

Items and activities that may be offered include

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- Twiddle muffs/fidget blankets

*These are examples of what may be offered with the VIP Program. Program offerings may vary.

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Background

Case Study: MW is a Resident in a Long-Term Care Facility

- MW used to enjoy reading the newspaper with her breakfast every morning, manicures and country music.

- The team placed a volunteer with her who reads the newspaper to her each morning while she has her breakfast. The HHA provides manicures and plays country music while providing care.

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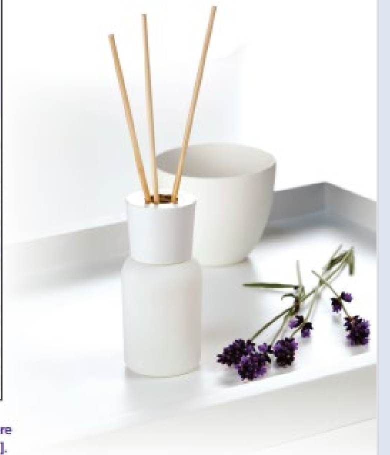

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Assessment

Case Study: MW is a Resident in a Long-Term Care Facility

VITAS social worker completed questionnaire with MW's daughter to create enjoyable, customized experience for MW.

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VITAS Individualized Pampering (VIP) Program (cont.)

- Clinicians complete a questionnaire for each resident to determine which VIP activities the resident may benefit from:
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5. What are some of the common careers that your residents had prior to being admitted to your facility?
6. Do you have many residents who are Veterans?

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Discussion and Recommendations

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Recommendations

Case Study: MW is a Resident in a Long-Term Care Facility

- Why is individualized care important for this resident?
- What are the risks of introducing too many "new factors" in care?
- What is the role of family members? Should they be involved continuously or only as needed? Why or why not?
- What does the trajectory of disease look like for this resident?

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Key Takeaways

- Dementia is a syndrome with a constellation of symptoms related to cognitive decline; most common cause is Alzheimer's
  - % of people with Alzheimer's increases with age; by age 80, 75% of people with Alzheimer's are admitted to a nursing home
- Dementia Care Practice Recommendations include 56 based recommendations across 10 areas
  - Person centered care involved recognizing and maintaining the self across the disease continuum, including creating opportunities to support a sense of self through meaningful relationships, activities and by eliciting values, preferences and choice
- Integrating a palliative approach to dementia can begin as soon as symptoms manifest and/or caregivers are impacted
  - Hospice eligibility occurs when persons are either FAST 7a, or for non Alz. Type show dependence in 3/6 ADLs plus complications r/t comorbidity or disease related complications in last 6 months
  - Hospice improves pain & symptom management & reduces burdensome transitions; plus improves family satisfaction with care

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Alzheimer's Association. 2022 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*. 2022;18(4):700-789. doi:https://doi.org/10.1002/alz.12638

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Harrison, K. et al. (2022). Hospice Improves Care Quality For Older Adults With Dementia In Their Last Month Of Life: Study examines hospice care quality for older adults with dementia in their last month of life. Health Affairs, 41(6), 821-830.

Irwin, S., et al. (2013). Association Between Hospice Care and Psychological Outcomes in Alzheimer's Spousal Caregivers. Journal of Palliative Medicine, 16(11), 1450-1454.

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Session Evaluation and Certificate of Completion

- Your feedback is valuable as we plan upcoming sessions! Please complete the Project ECHO Dementia Care Miniseries Post-Session Evaluation

- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for participants who complete all session evaluations as well as a final miniseries evaluation

ALZHEIMER'S® ASSOCIATION
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Upcoming Sessions

March 14

Person-centered Patient Assessment and Care Planning

March 21

Providing Information, Education & Support to Patients and Families

March 28

Transitions in Care and Coordination of Services

April 4

Building and Supporting an Empowered Workforce

April 11

Reimbursement, Regulatory, and Quality

April 18

Summary and Wrap-Up

ALZHEIMER'S ASSOCIATION® Project ECHO® NHPCO

Additional Information

NHPCO Project ECHO webpage:

https://www.nhpco.org/regulatory-and-quality/quality/projectecho/

For more information:

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