

NHPCO Project ECHO Key Takeaways

Best Practices in Dementia Care Spring 2024

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

Key points:

- 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

References:

- 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>
- Fazio S, Pace D, Maslow K, Zimmerman S, Kallmyer B. Alzheimer's Association Dementia Care Practice Recommendations. *The Gerontologist*. 2018;58(1):S1-S9. doi:<https://doi.org/10.1093/geront/gnx182>
- 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.
- Mitchell, et al. (2009). The clinical course of advanced dementia. *New England Journal of Medicine*, (361), 1529-1538.
- NHPCO Facts and Figures 2020 <https://www.nhpc.org/wp-content/uploads/NHPCO-Facts-Figures-2020-edition.pdf>



- Shega, J., et al. (2008). Patients Dying with Dementia: Experience at the End of Life and Impact of Hospice Care. *Journal of Pain and Symptom Management*, 35(5), 499-507.
- Dementia Care Practice Recommendations: https://www.alz.org/professionals/professional-providers/dementia_care_practice_recommendations



Session 2: Assessment and Care Planning

Key points:

- Use a whole person-centered, interdisciplinary approach in assessing patients with dementia.
- Utilize dementia specific resources such as the Alzheimer’s Association.
- When describing the situation of a patient with end stage dementia, paint a detailed picture of the patient to demonstrate the changes that occur as they may not be as obvious as large changes in weight or functional status.
- Capture increased caregiving requirements.

Participant Perspectives:

- Families often provide such excellent care at home that dementia patients live longer than expected.
- Asking families how long it takes the patient to finish a meal can be an important assessment tool.
- “I would request staff to document amount of time awake/sleep, amount of time to feed, amount of fluid intake and time to consume, increase in stiffness, changes to care needs, skin and adiposity changes, contractions, urine volume.”
- “I have learned with dementia patients to coach staff and ALF/NH staff to document these changes in detail from initial admit.”

References:

- Centers for Medicare and Medicaid Services (CMS) Local Coverage Determinations. Hospice – Determining Terminal Status <https://www.cms.gov/medicare-coverage-database/view/lcd.aspx?lcdid=33393&ver=5&=>
- National Institute on Aging <https://www.nia.nih.gov>
- Alzheimer’s Association <https://www.alz.org>
- Kim SK, Park M. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. Clin Interv Aging. 2017 Feb 17;12:381-397. doi: 10.2147/CIA.S117637. PMID: 28255234; PMCID: PMC5322939.
- Wisconsin Department of Health Services - Bureau of Aging and Disability Resources in collaboration with the Bureau of Quality Assurance Person-Directed Care Behavior Solutions Study Advisory Committee.



Session 3: Providing Information, Education, and Support to Patients and Families

Key Points:

- Caregiving burden for those caring for persons with dementia is significant
- Culturally relevant/responsive programs are important in dementia care
- One size does not fit all. It is critical to recognize the culture of all those we are trying to serve
- Education provided by people who look like those we are serving is often better received
- Black individuals are more likely than others to develop Alzheimer's type Dementia
- On an average, the onset of disease is early
- Compared to caregivers of patients with non-dementia related diagnoses, caregivers of patients with dementia-related diagnoses have higher levels of stress, are more isolated and have felt a sense of relief after the patient dies
- Best practice recommendations suggest that it is important to ensure that information, support, and resources are available at a time of transition, and that partners work together to plan care early on.
- When caregiving for persons with dementia, literacy, language, and cultural sensitivity are key factors for a successful and high-quality experience.

Actionable Steps:

- Provide education and support early in the disease to prepare for the future
- Encourage care partners to work together and plan together
- Build culturally sensitive programs that are easily adaptable to special populations
- Ensure education, information, and support programs are accessible during times of transition
- Use technology to reach more families in need of education, information, and support

Participant Perspectives:

- “Some may feel ‘survival guilt’ for feeling relief after caregiving issues are no longer required.”
- “Caregiving becomes so much a part of your fabric that you almost have to redefine yourself afterwards.”
- “Every time [the patient] exhibits a new decline, [the caregiver] could grieve that loss.”

References:

- Alzheimer’s Association. 2023 Alzheimer’s Disease Facts and Figures. Alzheimer's Dement 2023;19(4). DOI 10.1002/alz.13016. <https://www.alz.org/alzheimers-dementia/facts-figures>
- Zarit Burden Interview (ZBI) https://eprovide.mapi-trust.org/instruments/zarit-burden-interview#need_this_questionnaire
- Archangels Caregiver Intensity Index <https://www.archangels.me/for-organizations>
- Caregiving while Black: <https://scholarblogs.emory.edu/epps-faithvillage/research-projects/care/>



- <https://www.alz.org/help-support/caregiving/care-options/respite-care>
- <https://www.alz.org/professionals/professional-providers/center-for-dementia-respite-innovation>



Session 4: Transitions in Care and Coordination of Services

Key Points:

- Palliative Care clinicians are well-situated to support PLWD and their care partners in optimizing transitions of care.
- The focus of Palliative Care (person-centered and goal-concordant care) aligns perfectly with the strategies identified in the Dementia Care Practice Recommendations to reduce transitions of care.
- The interprofessional construct of Palliative Care and role of Palliative Care clinicians in promoting ideal communication between members of the care team positions them well to reduce fragmentation of care and poor outcomes from care transitions.
- Palliative Care clinicians can provide connections to support and resources in the community, enhancing quality of life for care partners and PLWD while also potentially reducing care transitions.
- Timely referrals to Hospice can reduce care unnecessary transitions at the end of life.

Actionable Steps:

- Prepare and educate persons living with dementia and their family caregivers about common transitions in care
- Ensure complete and timely communication of information between, across, and within settings
- Evaluate the preferences and goals of the person living with dementia along the continuum of transitions in care
- Create strong interprofessional collaborate team environments to assist persons living with dementia and their care partners/caregivers as they make transitions
- Initiate/use evidence-based models to avoid, delay, or plan transitions in care

Participant Perspectives:

- “I appreciate you mentioning the "moral distress" of family members who see their loved ones doing poorly after a transition. This is something I hear a lot from grieving families as a grief counselor.”

References:

- Alzheimer’s Association. 2023 Alzheimer’s Disease Facts and Figures. *Alzheimer’s Dement* 2023;19(4). DOI 10.1002/alz.13016.
- Amjad, H., Roth, D. L., Sheehan, O. C., Lyketsos, C. G., Wolff, J. L., & Samus, Q. M. (2018). Underdiagnosis of Dementia: an Observational Study of Patterns in Diagnosis and Awareness in US Older Adults. *Journal of general internal medicine*, 33(7), 1131–1138.
- Hirschman KB, Hodgson NA. Evidence-Based Interventions for Transitions in Care for Individuals Living With Dementia. *Gerontologist*.



- Kamdar N, Syrjamaki J, Aikens JE, Mahmoudi E. Readmission Rates and Episode Costs for Alzheimer Disease and Related Dementias Across Hospitals in a Statewide Collaborative. *JAMA Netw Open*. 2023;6(3):e232109.
- Matsuoka T, Manabe T, Akatsu H, et al. Factors influencing hospital admission among patients with autopsy-confirmed dementia. *Psychogeriatrics*. 2019;19(3):255-263.
- Mjørud, M., Selbæk, G., Bjertness, E., Edwin, T. H., Engedal, K., Knapskog, A. B., & Strand, B. H. (2020). Time from dementia diagnosis to nursing-home admission and death among persons with dementia: A multistate survival analysis. *PloS one*, 15(12), e0243513.



Session 5: Reimbursement, Regulatory, and Quality

Key Points:

- Important considerations
 - Dementia is a syndrome not a disease
 - Umbrella term of numerous diseases/disorders that cause symptoms cognitive/functional decline
 - Dementia is a terminal illness
- Many individuals with dementia and their caregivers were not told of their diagnosis
- Caregiver support is critical
- Patients should be routinely assessed for changes in their functional abilities
- Safety screening, specifically related to driving, is an important assessment point
- Behavior and psychological symptoms are common in dementia, and often not appropriately assessed or treated

Actionable Steps:

- Proactively provide education and support to patients and caregivers
- Assess functional status early and often, at least once per year
- Assess for safety considerations, including driving ability and polypharmacy
- Screen for behavioral and psychiatric symptoms and make recommendations for management
- Assess for the presence of advance care plans and surrogate decision-makers
- Avoid making too-many changes at one time

Participant Perspectives:

- The full Interdisciplinary Team can be very valuable to helping patients and caregivers navigate dementia care.

References:

- Dementia Quality Measurement Set https://www.aan.com/siteassets/home-page/policy-and-guidelines/quality/quality-measures/15dmmeasureset_pg.pdf
- CMS GUIDE Model <https://www.cms.gov/priorities/innovation/innovation-models/guide>
- Lawton Instrumental Activities of Daily Living Scale https://geriatrictoolkit.missouri.edu/funct/Lawton_IADL.pdf
- Barthel ADL Index <https://www.sralab.org/sites/default/files/2017-07/barthel.pdf>
- Katz Index of Independence in Activities of Daily Living <https://www.alz.org/careplanning/downloads/katz-adl.pdf>
- Functional Activities Questionnaire <https://www.alz.org/careplanning/downloads/functional-activities-questionnaire.pdf>
- Pain Assessment in Advanced Dementia (PAINAD) <https://geriatrictoolkit.missouri.edu/cog/painad.pdf>



- Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)
<https://geriatricpain.org/pacslac>
- Pain Assessment for the Dementing Elderly (PADE)
https://geriatricpain.org/sites/geriatricpain.org/files/2023-06/PADE_Final%20with%20logo.pdf



Session 6: Building and Supporting an Empowered Workforce

Key Points:

- Provide a thorough orientation and training program for new staff, as well as ongoing training
- Develop systems for collecting and disseminating person-centered information
- Encourage communication, teamwork, and interdepartmental/interdisciplinary collaboration
- Establish an involved, caring, and supportive leadership team
- Promote and encourage resident, staff, and family relationships
- Evaluate systems and progress routinely for continuous improvement
- The status quo is not working
- A trained and supported staff will excel
- The leader sets the tone, establishes the culture, and impacts quality of care and quality of life for residents/clients and the staff

Actionable Steps:

- Focus on retention instead of turnover
- Consider staff to acuity ratios
- Evaluate systems and progress routinely for continuous improvement

References:

- Dementia Care Practice Recommendations alz.org/qualitycare
- PHI - Quality Care Through Quality Jobs www.phinational.org
- The Commonwealth Fund - Policy Options to Advance Long-Term Care: Resources and Tools for State Policy Makers <https://www.commonwealthfund.org/blog/2023/policy-options-long-term-care-resources-tools-state-policymakers>
- <https://hov.wistia.com/medias/4upmedhb6k>
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