



Addressing the Palliative Care Needs of People Living with Dementia and their Caregivers

*National Alzheimer's Project Act (NAPA) Advisory Council
on Research, Care and Services*

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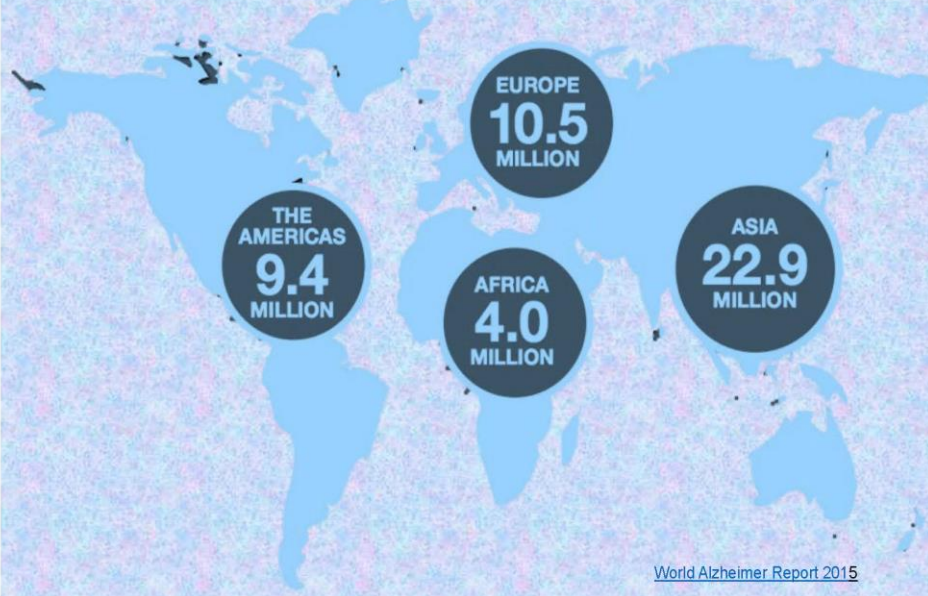
Goals for today

Briefly describe the epidemiology of dementia

Discuss gaps in dementia care experienced by persons with dementia and their carers

Reflect on how integration of palliative care can fill these gaps

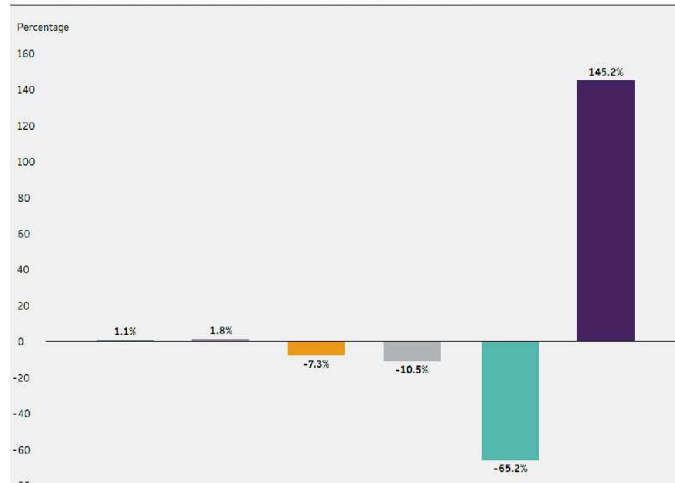
Every three seconds a new case of dementia develops around the globe



Epidemiology of Dementia



Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2019



Alzheimer's Association 2022 Facts and Figures

Epidemiology of Dementia

- 5.8 million people in US with ADRD
 - 5.6 million aged 65+
 - 200,000 <65 with younger-onset Alzheimer's
- By 2060, ADRD estimated to affect **14 million people**
 - Cases among Hispanic older adults will increase 7x over today's estimates.
 - Cases among Black older adults will increase 4x over today's estimates



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<https://www.cdc.gov/aging/publications/features/Alz-Greater-Risk.html>

Dementia public health impact in the United States

- Only major chronic disease with **NO effective treatment**
- **>1 million have advanced dementia**
- Overall costs \$305 billion
- Caregivers average 22 hours/ week x 3yrs
- Family expenditures \$66,000 in last year of life – **HIGHEST** cost of any disease



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Wong W. AJMC 2020 26, Issue 8; 2020 Alzheimer's disease facts and figures.
<https://alz-journals.onlinelibrary.wiley.com/doi/epdf/10.1002/alz.12068>

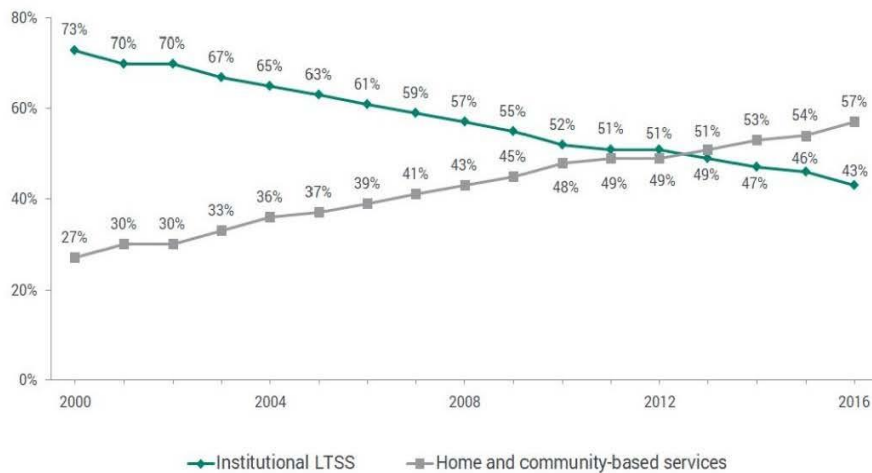
Dementia— no longer mainly institutional care

But also in the community:

2.1+ million older adults live at home with mod-severe dementia

Harrison KL, Ritchie CS, Patel K, et al. *J Am Geriatr Soc.* 2019;67(9):1907-1912.

Dementia in the Community

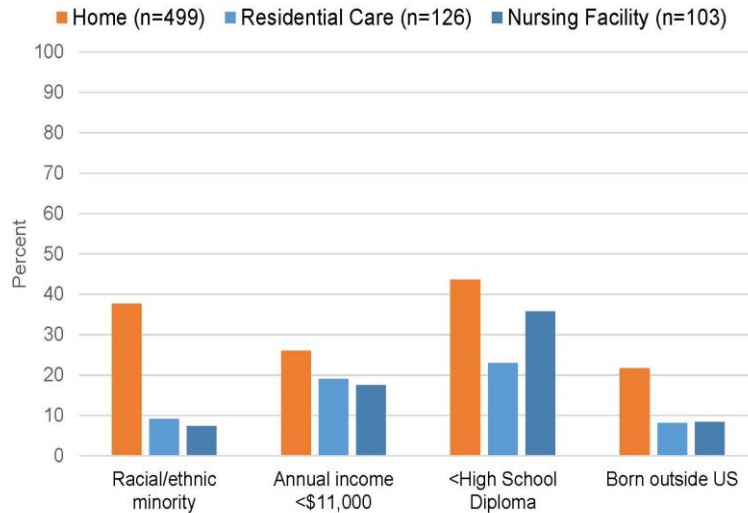


Proportion of Total Medicaid LTSS Spending on Institutional LTSS and HCBS: 2000-2016

<https://www.macpac.gov/subtopic/home-and-community-based-services/>

Dementia at Home: More Social Vulnerabilities

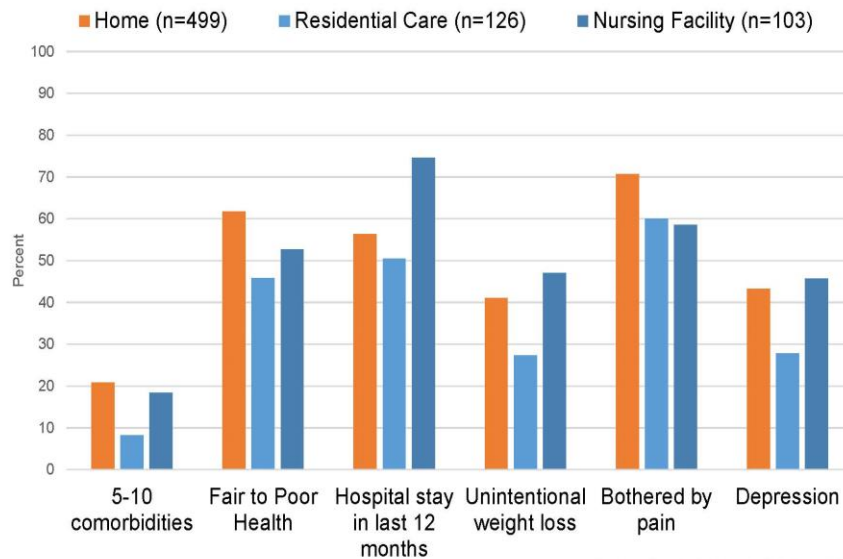
incident moderately severe dementia



Harrison KL et al. J Am Geriatr Soc. 2019 Sep;67(9):1907-1912.

Dementia at Home: High Clinical Needs

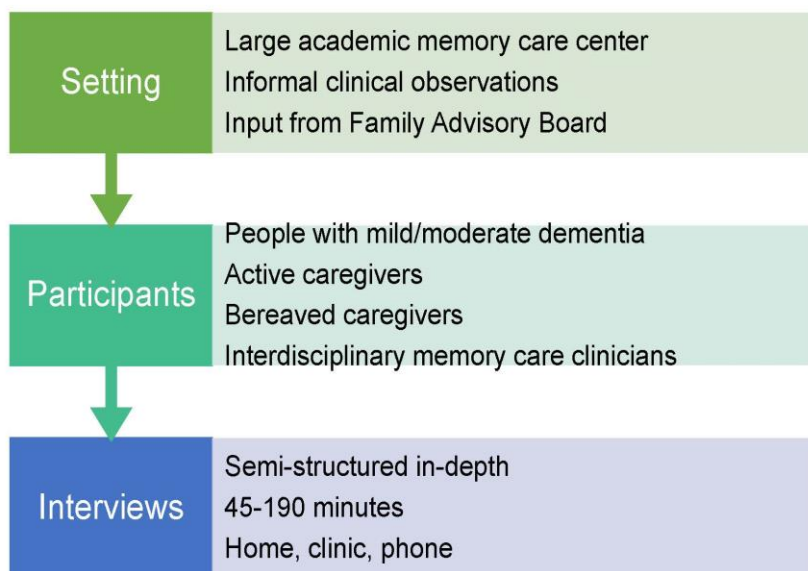
incident moderately severe dementia



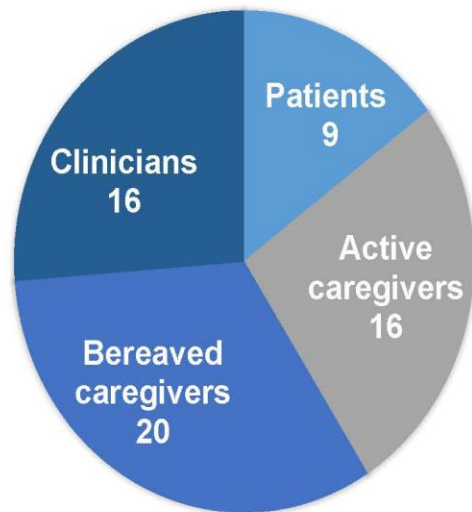
Harrison KL et al. J Am Geriatr Soc. 2019 Sep;67(9):1907-1912.



Seeking to Understand the “D” Journey



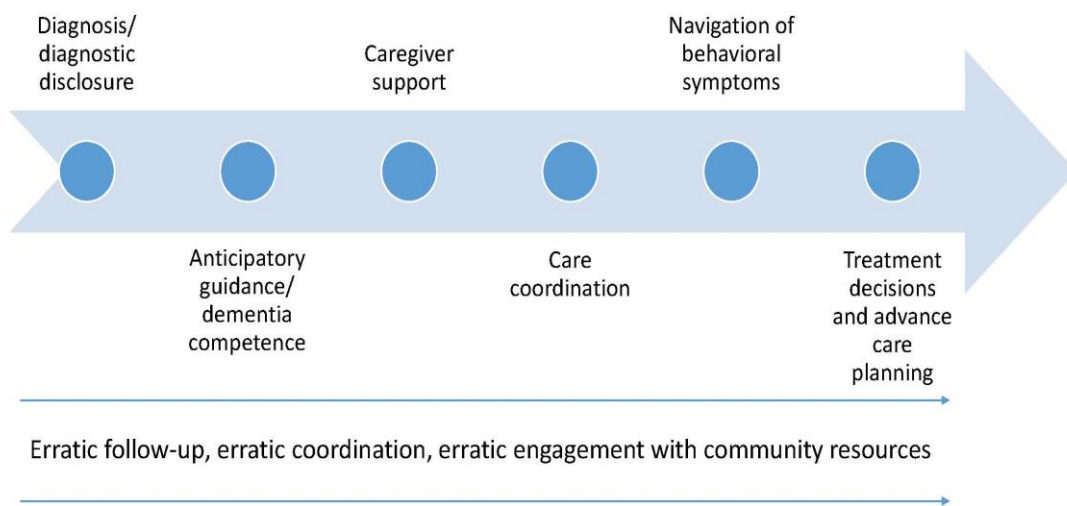
Recruitment



Harrison et al. J Alz Dz
2022; in press

13

Living with dementia in the community: gaps



Unmet needs—diagnosis without attention to disclosure

Provider

I think we are on a mode of, “Oh, I’m just here to diagnose.” Diagnose and adios, and then someone else will take care of these things.

- Neurologist

Caregiver

The meeting at [institution] felt “like surgery without the benefit of anesthesia,” [caregiver]] later wrote in her journal. “There were no buffers . . . no words of hopefulness, just blunt, sharp words like ‘widespread cognitive decline.’

- *Caregiver

Bernstein et al, In press; https://www.bostonglobe.com/metro/2019/10/27/charles-and-pam-ogletree-long-last-walk-love/fHcJ2LrJ6lOtie8P7MBLzL/story.html?utm_source=pocket-newtab

Unmet needs—anticipatory guidance

Prognosis
and expected
disease
trajectory

Disease
trajectory

Unique
dementia
syndromes

Uncertainty

Clarity of
dementia as
a terminal
condition

Behavioral,
safety, and
caregiving

Safety

Behavior

Caregiving

Planning for
the future

Financial and
legal

Advance care
planning

Change in
living/care
settings

Adapted from Shafir A, Ritchie CS, et al. J Alzheimers Dis. 2022 PMID: 35124641

Unmet needs—anticipatory guidance

Caregiver

I guess my frustration is I don't know what to expect... I would like to ask Dr. X, you know, "What's the end game? What's going to happen?" and nobody's able to tell me, and maybe they can't... That's the very <sighs> frustrating part. **This feels like a slow-motion car crash.**"
-Caregiver

"It would have been helpful to my family if all three of us could... realize things that had to be decided, and have a better plan... You just don't know what's ahead, so how do you plan for what's ahead?...Do you risk the infection, or do you have the tooth extracted?"
-Caregiver

Bernstein et al.

Unmet need for caregiver support

- Uncertainty about the future
- Lack of knowledge of resources available
- Caregiver burden and burnout
- Isolation
- Cost and quality of paid caregivers.



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Harrison et al. JAGS Supplement 2020

Unmet need for caregiver support

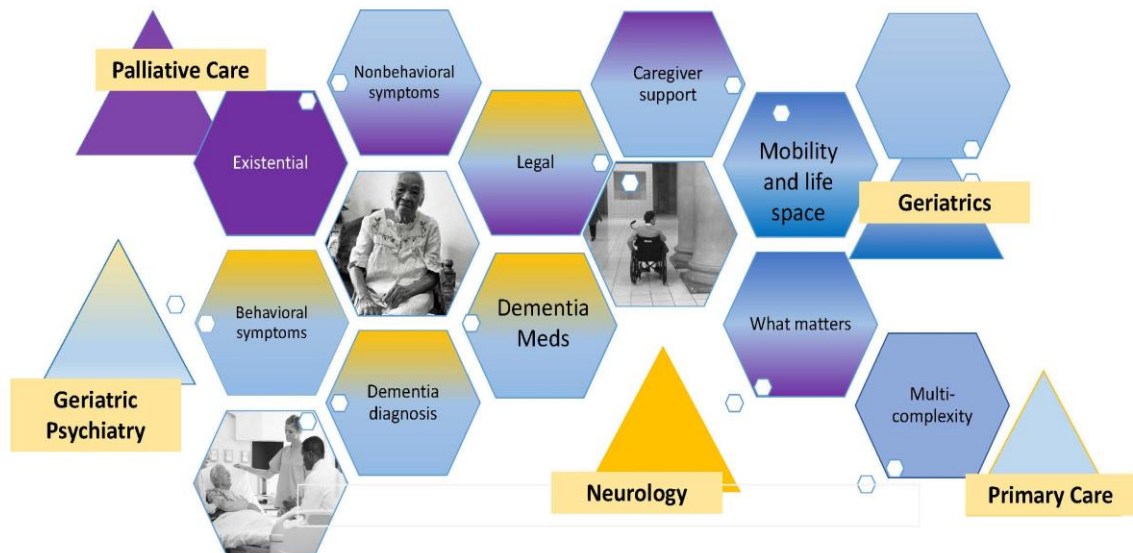


“...it just seemed like everybody went to that expression, ‘Make sure you take good care of yourself.’ Well, really? I’m on call 24 hours a day. I’m dealing with something I am clueless about and I don’t know where it’s going and how fast it’s going and my wife is disappearing. It’s not an easy thing to navigate. ”

-Caregiver

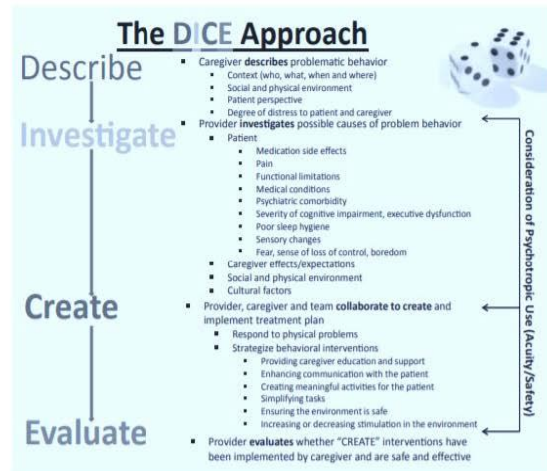
Harrison et al. JAGS Supplement 2020
 Painting: Our Life with DLB by Artist and caregiver (with permission)

Unmet Need: Care Coordination



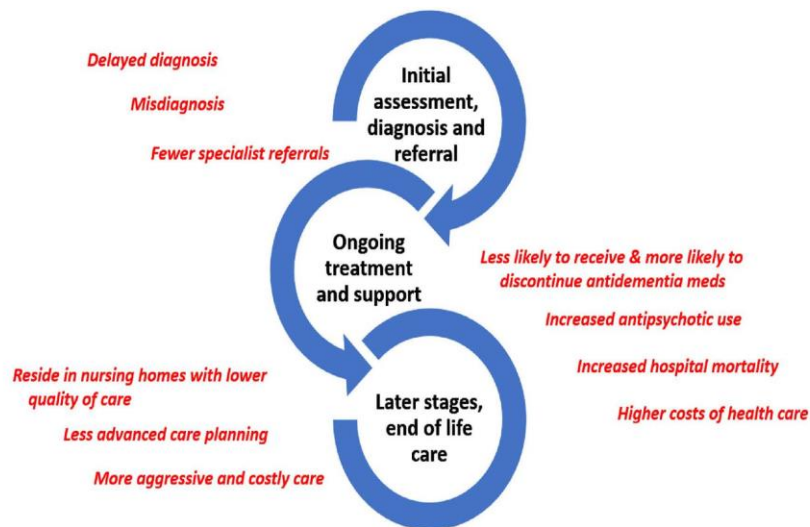
Unmet Need: Management of Behavioral Symptoms

- Depression
- Psychosis
- Apathy
- Agitation
- Aggression
- Delusions
- Hallucinations
- Sleep disturbances
- Wandering and argumentativeness



Kales HC et al. J Am Geriatr Soc. 2014 Apr;62(4):762-9. PMID: 24635665; PMCID: PMC4146407.

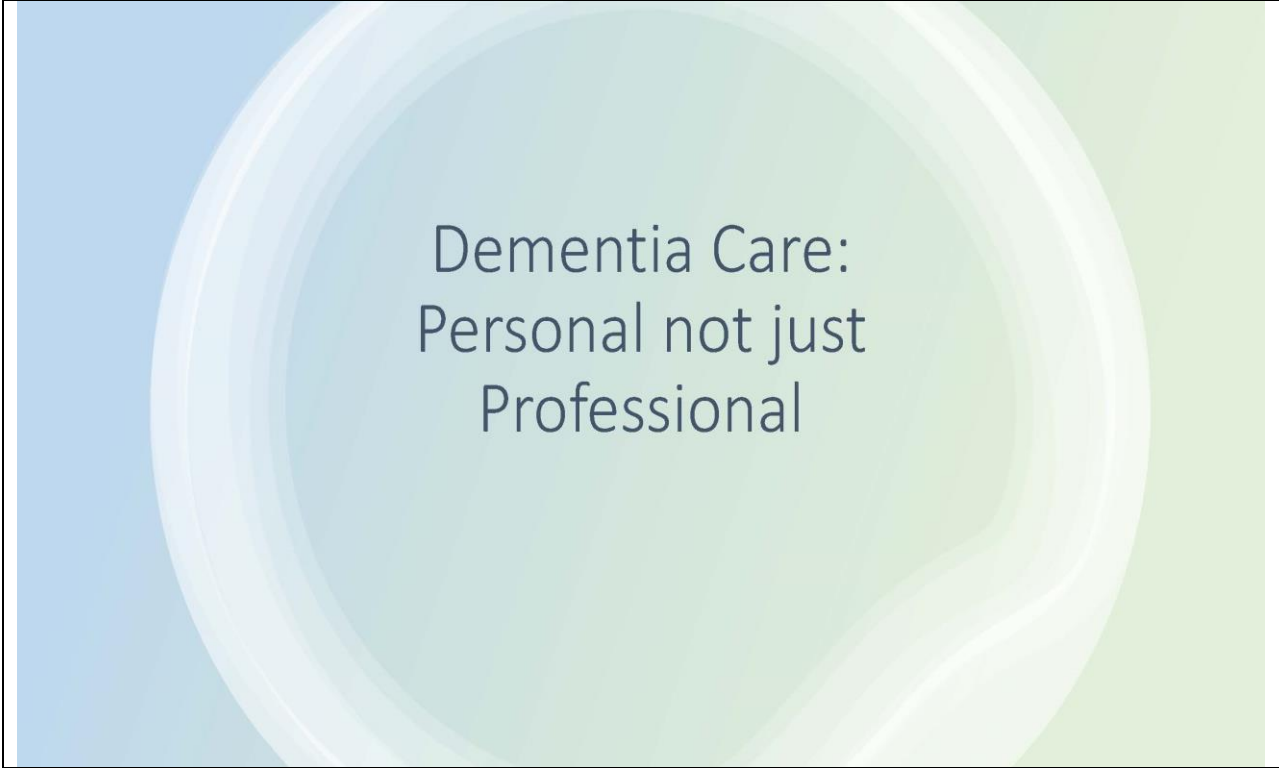
Care gaps exacerbated in minority populations



Journal of the American Geriatrics Society, Volume: 69, Issue: 7, Pages: 1774-1783, First published: 10 July 2021, DOI: (10.1111/jgs.17345)

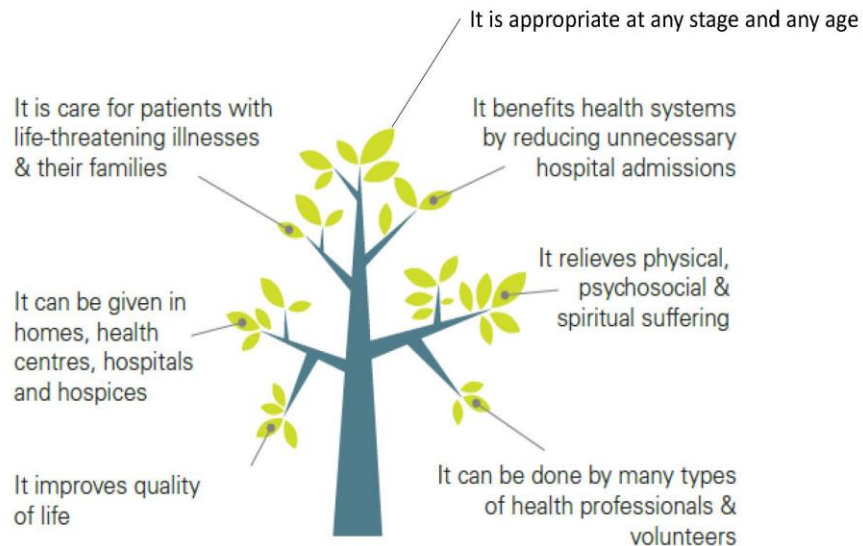
Aspirations from the National Strategy to Support Family Caregivers

- “Be informed advocates...(and) obtain the services they desperately need to survive and thrive.”
- “Access the right support at the right time.”
- “Maintain their own vitality, health, and wellness.”
- “Protect the bonds of family...and maintain strong family relationships.”
- “Navigate services that support their needs for providing a service of care.”
- “Access emotional and financial support without judgment.”
- “Reference a living document that reflects shared values.”
- “Breathe again...”



Dementia Care:
Personal not just
Professional

What is palliative care?



http://www.who.int/ncds/management/palliative-care/infographic_palliative_care_EN.pdf?ua=1

Unique Palliative Care Challenges of Dementia

No benefits of a “terminal illness”

- An uncertain future
- Limited hospice access

Pain, neuropsychiatric (nontraditional) symptoms common

- Assessment skills / tools differ
- Effective therapy is ? + medication + environment

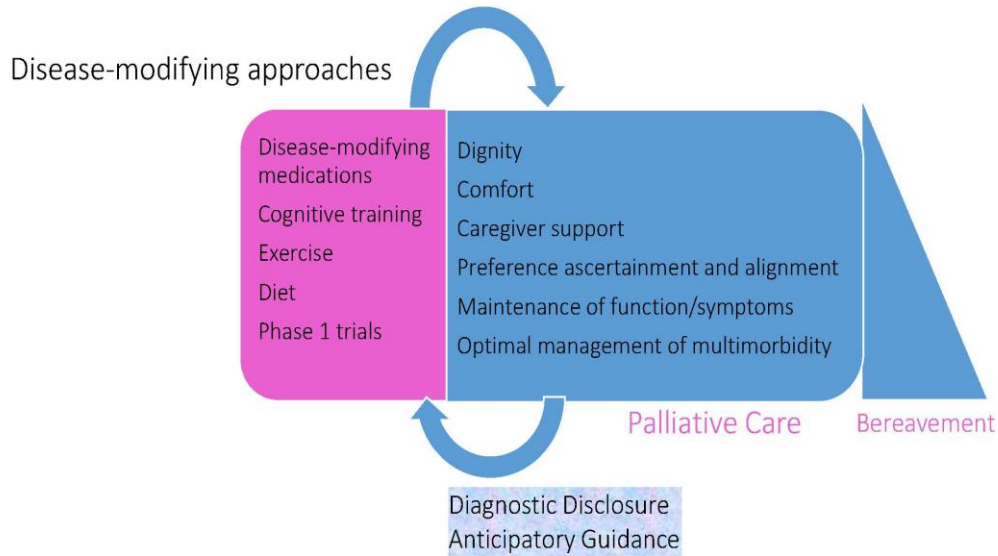
Many Decisions – feeding, hospital transfers, antibiotics

- Need for surrogate decision-making
- MD often “missing in action” – nurse-led care

Prolonged and unique anticipatory grief

Morrison RS, JAMA 2000; Husebo BS, BMJ 2011; Mitchell SL, NEJM 2009; Teno JM JAMA 2013, Hanson, LC, JAGS, 201; Shield RR JAGS 2005; Biola H JAGS 2007

Palliative Care in Dementia



Adapted, Volicer L, Simard J Int Psychogeriatr 2015

Integration of Palliative Care into Dementia Care

	Sources of Distress & Challenge	Sources of Support
Disease-oriented	Distressing manifestations (symptoms, behaviors, functions) Implications (uncertainty, loss) Lack of accessible/affordable resources	Information, programs, resources Activities & strategies to manage symptoms Support groups
Social & relational	Relationship changes within social network Loss of relationship with PLWD Constrained social & professional opportunities Grief (incremental, anticipatory, and post-death)	Engaging PLWD in social activities Grieving supports & strategies
Caregiving	Obligations of caregiving Family misalignment about care/decisions Toll of caregiving	Tangible help with instrumental and basic activities of daily living, housework Help with paperwork and planning Resilience strategies Enabling factors (prior experience, connections)
Clinical care & systems	Impact of assessments and diagnosis Insufficient guidance from specialty dementia center Lack of expert dementia knowledge; issues with medications Care fragmentation and system gaps	Information and guidance (including diagnosis) Clear, supportive, timely interactions with clinicians Service types including specialty dementia care, home-based services, hospice, palliative care, geriatrics

Harrison et al. J Alz Dz 2022; in press

White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care

Palliative Medicine
2014, Vol. 28(3) 197-209
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DOI: 10.1177/0269216313493685
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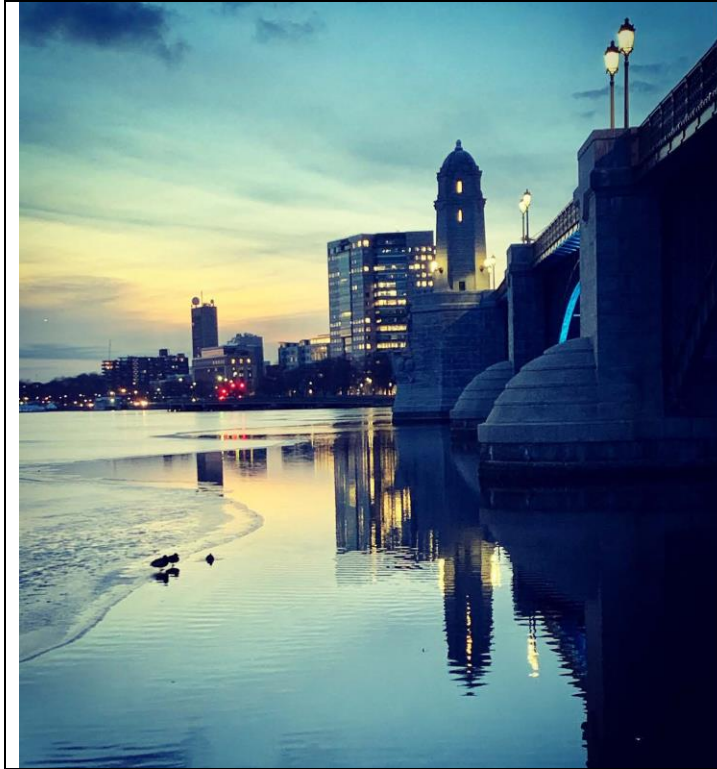
- Person-centred care, communication and shared decision-making
- Setting care goals and ACP
 - Continuity of care
 - Prognostication and timely recognition of dying
 - Avoiding overly aggressive, burdensome or futile treatment
- Optimal treatment of symptoms and providing of comfort
- Psychosocial support
- Spiritual support
- Family care and involvement
- Education of the healthcare team

SUMMARY

- Care gaps are numerous in dementia care
- A palliative care approach that keeps persons with dementia and their caregivers at the center will be a key driver in high quality dementia care



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Thankyou!

Questions?

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