

# Dementia Care Gaps and Recommendations for Improving Clinical Care and Quality of Life for People Living with Dementia and their Care Partners

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



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San Francisco

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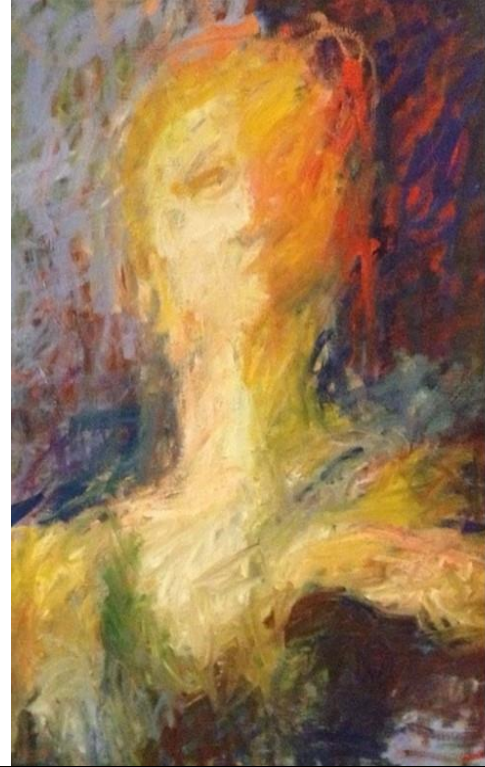
## Goals for today

PLWD and Caregiver Perspectives

Gaps in Clinician-Family  
Communication, ACP, Care Sites

Gaps in the diagnostic process  
(Dr. Sideman)

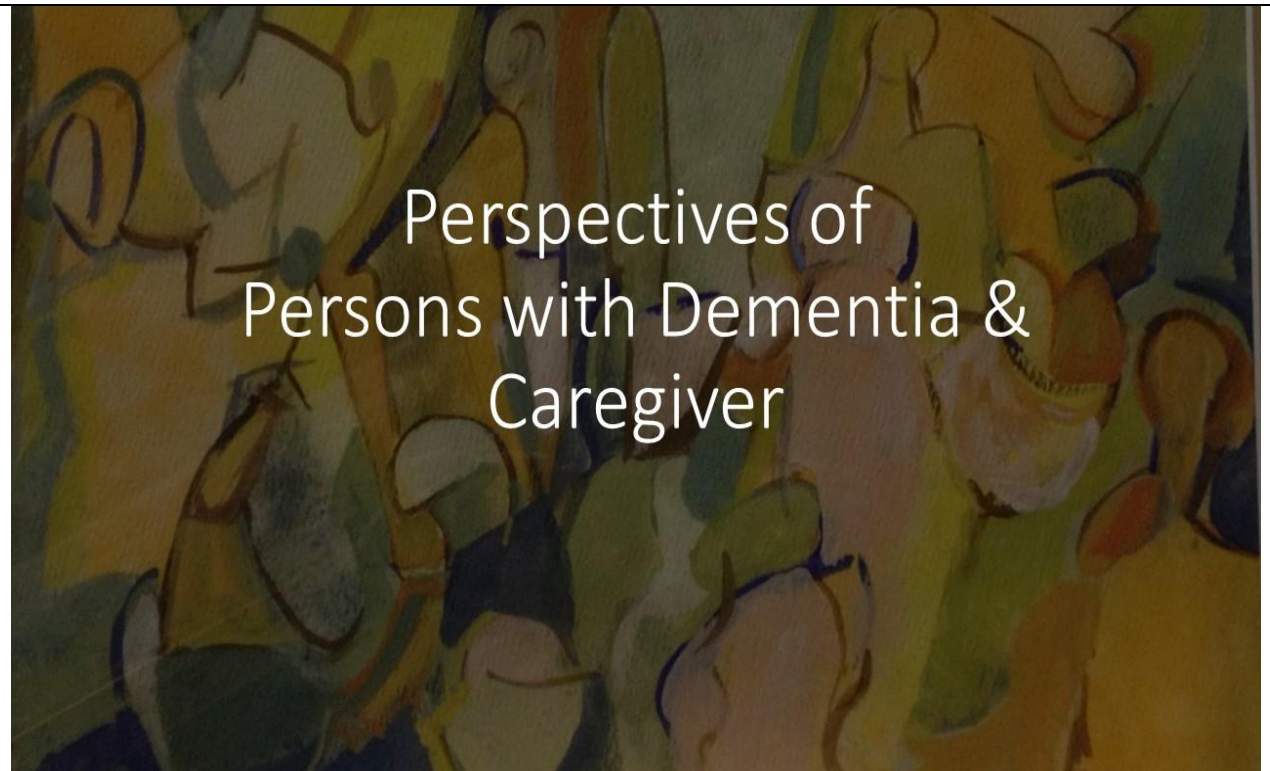
Recommendations



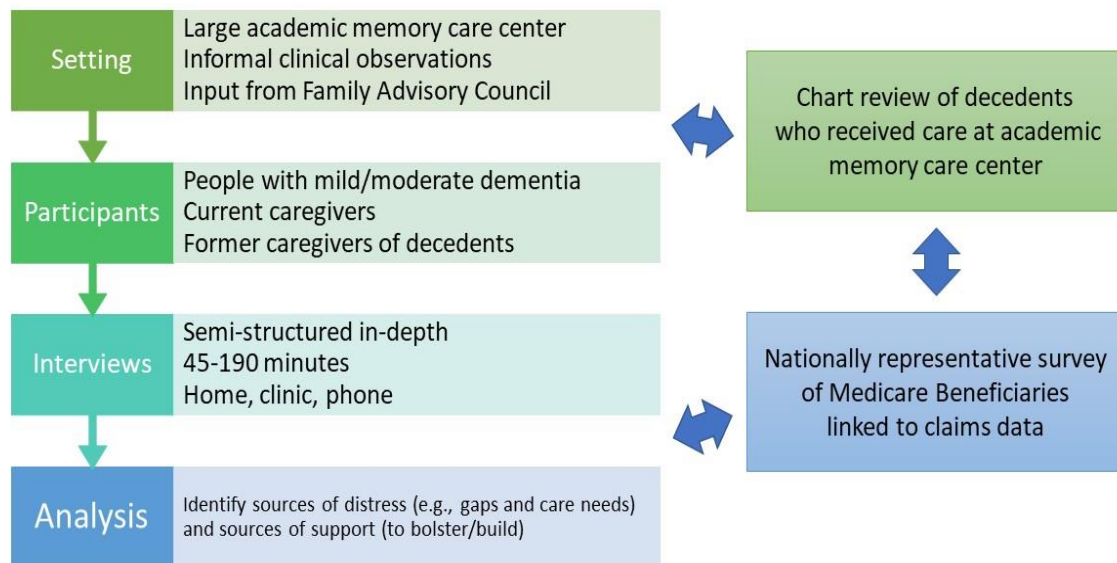
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No conflicts of interest to report



# Seeking to Understand Geriatric Palliative Needs in Dementia



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

Harrison KL et al. J Alzheimers Dis. 2022;90(3):1301-1320.

## Sources of Distress in ADRD: Disease-oriented

- **Disease manifestations:** symptoms, disability, falls, behaviors
  - *“Last night, in the middle of the night, he was hitting me and kind of screaming in his sleep, and I tried to wake him up. It seemed, in his dream, only to provoke him more and he really became physically violent”* (current caregiver for spouse with AD/VD)
- **Lack of accessible or affordable resources:** clinical settings and support groups challenging with severity of impairments
- **Complications:** comorbidities

Harrison KL, Garrett SB, Halim M, Bernstein Sideman A, Allison TA, Dohan D, Naasan G, Miller BL, Smith AK, Ritchie CS. "I Didn't Sign Up for This": Perspectives from Persons Living with Dementia and Care Partners on Challenges, Supports, and Opportunities to Add Geriatric Neuropalliative Care to Dementia Specialty Care. *J Alzheimers Dis.* 2022;90(3):1301-1320.

## Sources of Distress: Disease-oriented

- **Anticipation:** PLWD and current caregivers fear and struggle with uncertainty of disease progression, loss of independence, dependence in activities of daily living
  - *“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.”* (former caregiver to spouse with CBS, PCA)
- **Losses:** of control, privacy, independence for PLWD; frustration and shame at changes

Harrison KL et al. *J Alzheimers Dis.* 2022;90(3):1301-1320.

## Sources of Distress: Caregiver-oriented

- **Obligation:** *“When Black people raise their children, they teach their children always take care of their mother. It’s a lot, and that means do whatever is necessary...a lot of Black people will not put their parents in nursing homes and leave them there”* (former caregiver to mother with AD).
- **Physical, mental, financial toll:** *“I actually thought about suicide at that time. ... I was pretty sure where [Spouse] was going... and then having lost my job... I really kind of lost my identity”* (former caregiver to spouse with LBD).

Harrison KL et al. J Alzheimers Dis. 2022;90(3):1301-1320.

## Sources of Distress: Social and relational

- Impact of diagnosis and disease on relationships, including stigma
  - *“People, since they know that he has Alzheimer disease, they treat him differently. Like, you know, they think that he’s not capable of fellowship [at church]...and then they don’t want to get involved”* (current caregiver of husband with AD).
- Constraint of social and professional opportunities
- Caregiver distress at role changes and loss of vision of future
- Incremental, anticipatory, and after-death grief

Harrison KL et al. J Alzheimers Dis. 2022;90(3):1301-1320.

## Source of distress: clinical care

- **Fragmented care system:** *"We would see a social worker, or a therapist, and they were wonderful. We'd sit there and talk and everything. And they said they would follow up with us, and they never did. We never heard from anybody"* (former caregiver to spouse with CBS, PCA)
- **Medications:** polypharmacy, interactions, and side effects
- **Hospitalization:** problems with medications, worry care quality lower because of diagnosis and/or DNR order

Harrison KL et al. J Alzheimers Dis. 2022;90(3):1301-1320.

## Source of distress: clinical care

- Receipt of diagnosis surprising and concerning
- Two of 9 PLWD participants considered suicide:
  - *"At first when I got the diagnosis, I was ready to kill myself."*  
PLW nfVPPA, PSP

Harrison KL et al. J Alzheimers Dis. 2022;90(3):1301-1320.



# Gaps in the Diagnostic Process

Alissa Bernstein Sideman

## Gaps during the ADRD diagnostic process: perspectives of people living with dementia, their caregivers, and clinicians

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No conflicts of interest to report



# Goals

- Identify the gaps in the dementia diagnostic process
- Discuss impacts of receiving a dementia diagnosis

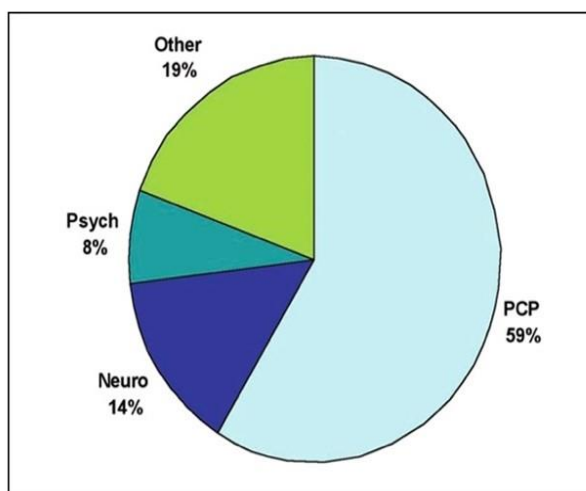
*"After two years of me saying, 'There's something not right and that's not normal,' he [primary care doctor] finally said, 'I think maybe it's time that you have him tested.' After seeing him a few times after the diagnosis, I finally said, 'Are you comfortable dealing with this?' Because to me it felt like he wasn't."*

*-Caregiver*

*"You start to learn, "Okay. I'm good at all the diagnostics," but then as you follow the lives of these patients you realize that there's more to this than just diagnosis. There's so much doctoring involved. **Just being there listening, talking, educating, that's harder to teach.**"*

*-Neurologist*

## Dementia Assessment and Management



- Most dementia cases are managed by PCPs<sup>1</sup>
- Missed and delayed diagnosis are common in primary care
- As many as 66% of patients are not diagnosed in early stages of the disease<sup>2</sup>

<sup>1</sup>New Patient Starts on Alzheimer Therapy (20400) by Specialty Source: Verispan VONA, New Patient Starts USC 20400 Alzheimer's Disease Therapies, June 2006 - May 2007.

<sup>2</sup>Boustani M, Peterson B, Hanson L, Harris R, Lohr KN, Force USPST. Screening for dementia in primary care: a summary of the evidence for the U.S. Preventive Services Task Force. *n Ann Intern Med.* 2003 Jun 3;138(11):160. PMID: 12778314; *Ann Intern Med.* 2003;138(11):927-937.

<sup>3</sup>Hinton L et al. Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. *J Gen Intern Med.* 2007;22(11):1487-1492.



# Methods & Participants

**This work draws on qualitative interviews with the following groups:**

- Primary care providers (physicians and nurse practitioners) from safety net settings across California
- Interdisciplinary memory care clinicians (neurologists, neuropsychologists, nurses, social workers)
- People living with dementia, active caregivers, and bereaved caregivers in California, Nebraska, and Iowa

## Primary care provider perspectives

### Strengths:

- Longitudinal, trusting relationships with patients
- Holistic understanding of patients' lives

### Gaps:

- Finding time to do a dementia workup when patients have other uncontrolled chronic conditions
- Symptoms of trauma, depression, substance abuse, and dementia are hard to disentangle
- Challenges related to communication with specialists
- Wide variation in knowledge and training
- Discomfort delivering a diagnosis, educating patients and families, prognosticating<sup>2-5</sup>



*"Trust is a big thing. Dementia is scary for patients. **Having that core of trust in the relationship** and being able to guide patients and caregivers through that is golden."*

*"I look back and see 'Do MOCA at the next visit' for 3 years. I finally did and it was a 13 and I thought 'Oops, I **should have done that earlier.**'"*

*"I wish I had more geriatric training...those are skills that would be so useful to me in the clinic setting where I am now where I need to take care of these patients and **don't have the resources to refer them.**"*

<sup>4</sup>Bernstein A, Rogers KM, Possin KL, et al. Dementia Assessment and Management in Primary Care Settings: A Survey of Current Provider Practices in the United States. *BMC Health Serv Res*. 2019.  
<sup>5</sup>Bernstein A, Rogers KM, Possin KL, Rankin KP, et al. Primary Care Provider Attitudes and Practices Evaluating and Managing Patients with Neurocognitive Disorders. *J Gen Intern Med*. May 2019.  
doi:10.1007/s11606-019-05013-7

## Interdisciplinary memory care clinician perspectives



### Strengths:

- Correct misdiagnoses and provide accurate diagnoses
- Help families better understand and manage symptoms

### Gaps:

- Tedious diagnostic process can be draining for PLWD and families
- Emphasis on diagnosis at expense of prognosis, anticipatory guidance

*"A lot of patients **jump from doctor to doctor** and they never hear a solid hypothesis. I find it useful when you sit down with a patient and the family and say, **"This is what I think it is."***

*"The attending will say, "So where's the anatomy? What's the clinical syndrome? What's the underlying pathology?" Why not just add one question **"Where is this person in terms of their concept of the disease?"** or, **"Are they struggling?"***

## PLWD and caregiver perspectives



### ▪ **Challenges when raising cognitive concerns**

- Language and cultural barriers
- Prioritization of other issues
- Gatekeeper clinicians

### ▪ **Caregiver involvement**

- Need for better ways of identifying and involving family members- including "family of choice"
- Better resources and support needed for caregivers

### ▪ **Convoluting referral processes**

- Structural challenges (transportation, access to referrals, insurance)
- More clarity about the purpose of referrals
- Lack of communication between PCPs, specialists, and families

*"I would say **the diagnostic road has certainly been unclear to me.**"*

*"What her primary care physician was saying was that she's just a little forgetful. Then you wait three months and things are worse, and I was like, **'You just don't get it,' because you do see something different at home.**"*

## PLWD and caregivers: impact of receiving a diagnosis



### ■ Clinician communication of diagnosis

- **What works:** attentive, empathetic, clear and direct communication
- **Challenges:** lack of clarity surrounding diagnostic disclosure, confusing or lack of anticipatory guidance, lack of clarity about prognosis

*"He confirmed, "Yeah, you've got Alzheimer's." Done. Adios. He didn't say "Get out," but, I mean, I don't think I was there more than 10 or 15 minutes. **No recommendations about what to do or come back or where to go.**"*

### ■ Emotional impacts of receiving a diagnosis

- Surprise, despair, suicidal ideation
- Confusion when there are multiple diagnoses or change in diagnosis
- Conflict in acceptance among family
- Relief in getting a diagnosis
- Diagnosis leading to improved care, treatment, and support

*"[Doctor] was very attentive not only to the words of the question, but also to the **emotional content** behind it...I think in terms of **presence with the patients and ability to meet someone at their level** and to speak with them well, he was great."*

## Gaps in Clinician-Family Communication

## Source of Distress: Lack of prognosis & guidance from clinicians

*"I guess what I would really like to know is 'What's going to happen next? What's the next thing that's going to happen... with this type of dementia? I mean, does he just quit eating? Does he just quit breathing? "*

(current caregiver of husband with bvFTD)

Shafir A, Ritchie CS, Garrett SB, Bernstein Sideman A, Naasan G, Merrilees J, Widera E, Flint L, Harrison KL. "Captive by the Uncertainty"-Experiences with Anticipatory Guidance for People Living with Dementia and Their Caregivers at a Specialty Dementia Clinic. J Alzheimers Dis. 2022;86(2):787-800.

## Domains of Desired Anticipatory Guidance

### Theme 1: Prognosis and expected disease trajectory

Anticipated disease  
trajectory and  
timeline

Unique aspects of  
specific dementia  
syndrome

Provide expected prognosis  
while acknowledging  
uncertainty

Clarity of dementia as  
terminal condition

### Theme 2: Behavioral, safety, and communication issues

Safety  
• Driving  
• Gun safety  
• Wandering

Behavior  
• Forewarning on  
common behavioral  
challenges

Communication  
• Advice on  
communication  
strategies

### Theme 3: Planning for the future

Financial and legal  
• Financial power of attorney  
• Will and trust  
• Fraud prevention

Advance care planning  
• Name and document surrogate decision  
maker  
• Assist in completion of advance directive

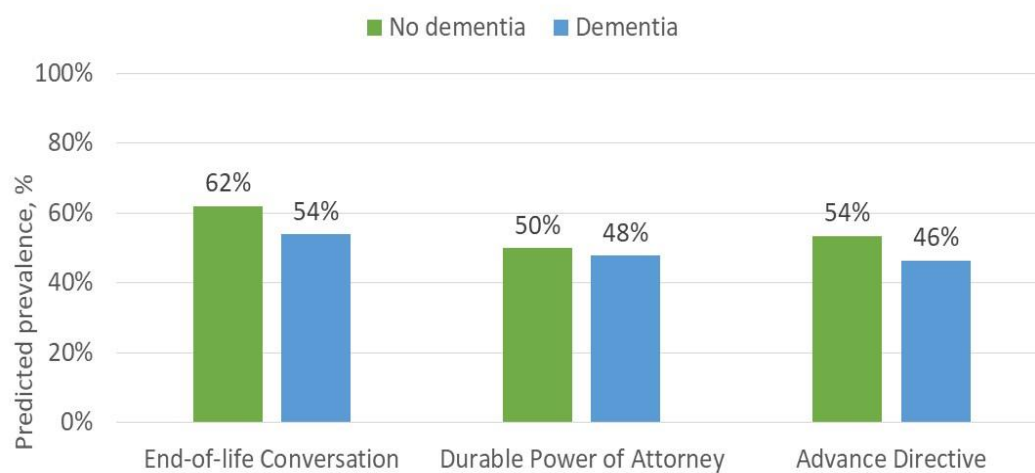
Transitions of care  
• Considerations on managing  
at home vs. transition to  
facility

Shafir A. J Alzheimers Dis. 2022;86(2):787-800.



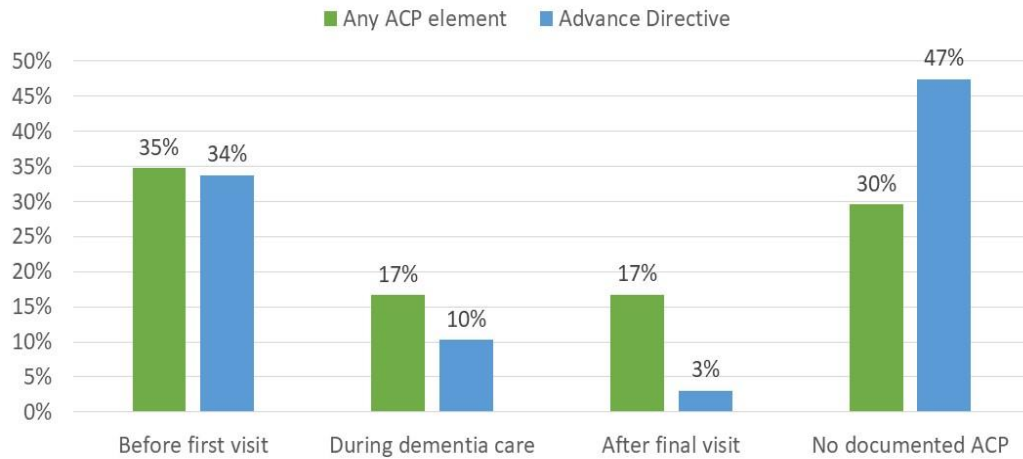
# Unmet need: Advance Care Planning (ACP)

## Advance Care Planning: national surveys



Harrison KL, Adrion ER, Ritchie CS, Sudore RL, Smith AK. Low Completion and Disparities in Advance Care Planning Activities Among Older Medicare Beneficiaries. JAMA Intern Med. 2016 Dec 1;176(12):1872-1875.

## Advance Care Planning: Memory Care Clinic



Naasan G, Boyd ND, Harrison KL et al. Advance Directive and POLST Documentation in Decedents With Dementia at a Memory Care Center: The Importance of Early Advance Care Planning. *Neurol Clin Pract*. 2022 Feb;12(1):14-21.

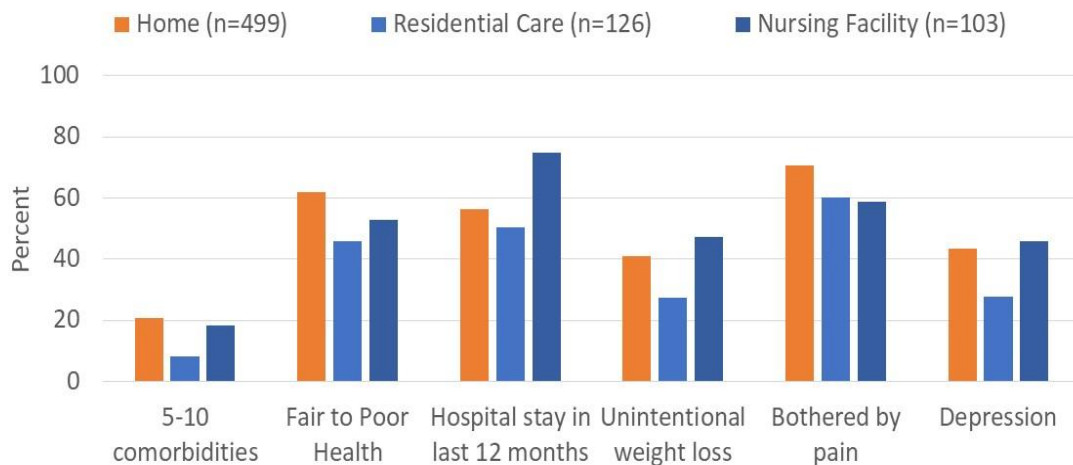
Gaps in Sites of Care

## Clinic-based care challenging over time

- Among PLWD seen at a specialized memory care center, 42% became lost to follow-up before death.
- Commonly documented reasons for not returning for clinic care
  - logistical difficulty accessing care (26%)
  - functional challenges in accessing care (23%)
  - patient-family decision to discontinue care (24%)
- Opportunities for future services: home-based care

Boyd ND, Naasan G, Harrison KL, Garrett SB, D'Aguiar Rosa T, Pérez-Cerpa B, McFarlane S, Miller BL, Ritchie CS. Characteristics of people with dementia lost to follow-up from a dementia care center. *Int J Geriatr Psychiatry*. 2022 Jan;37(1).

## @Home with Dementia and Severe Disability Have High Clinical Needs



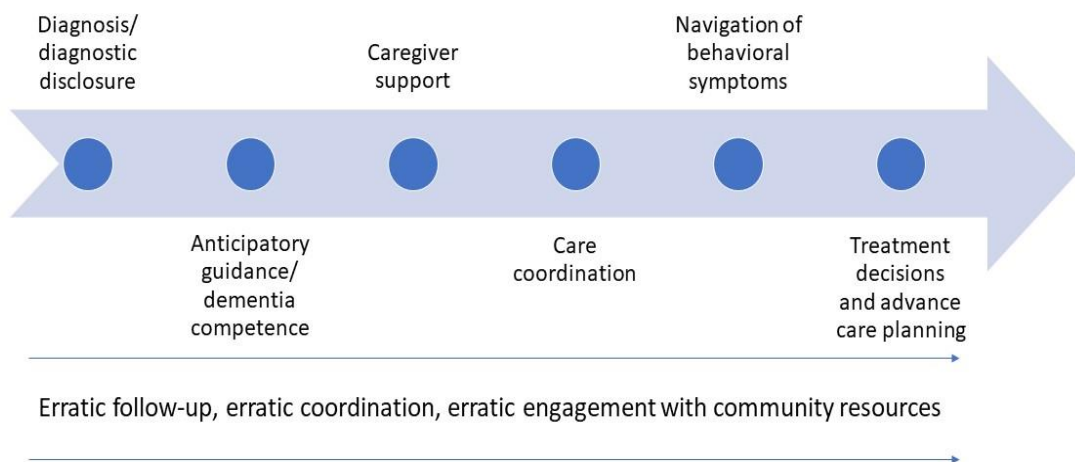
Harrison KL, Ritchie CS, Patel K, Hunt LJ, Covinsky KE, Yaffe K, Smith AK. Care Settings and Clinical Characteristics of Older Adults with Moderately Severe Dementia. *J Am Geriatr Soc*. 2019 Sep;67(9):1907-1912.

## Profound Need for Care at Home

- 44% PLWD received home-based clinical care vs. 14% of those without dementia
- PLWD receive 5x more home-based medical care, 2x more skilled home health, than people with no dementia
- Need for payment models that support interdisciplinary clinical, functional, and social care at home before end-of-life

Ornstein KA, Ankuda CK, Leff B, Rajagopalan S, Siu AL, Harrison KL, Oh A, Reckrey JM, Ritchie CS. Medicare-funded home-based clinical care for community-dwelling persons with dementia: An essential healthcare delivery mechanism. JAGS. 2022 Apr;70(4):1127-1135.

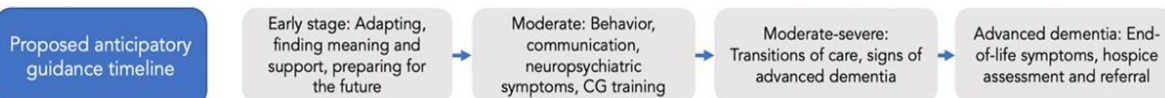
## Summary of Gaps in Clinical Care





# Recommendations for Clinical Care Approaches

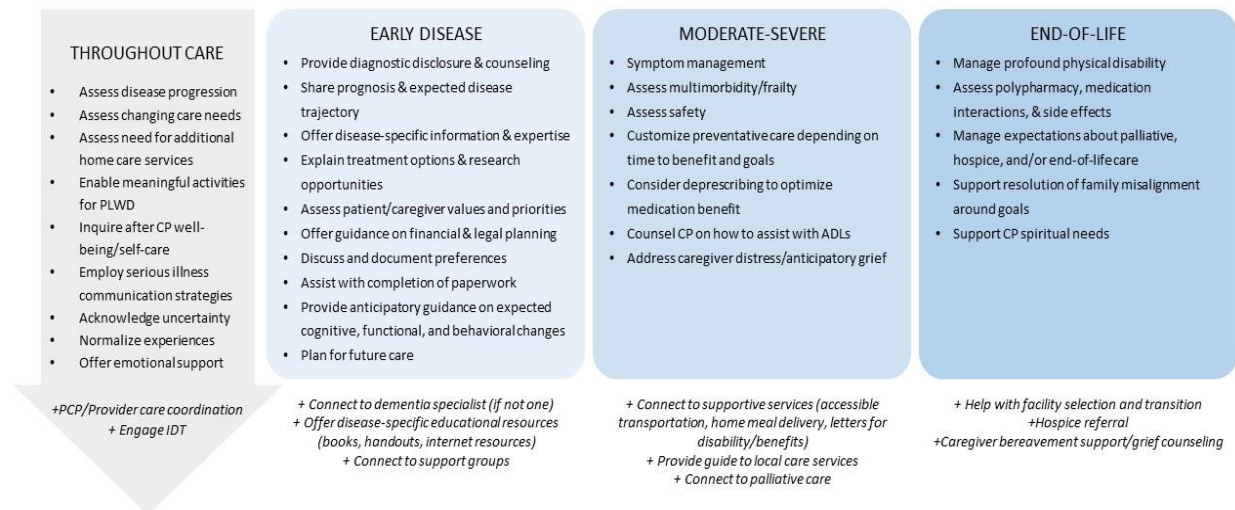
## Anticipatory Guidance



|                                                                                  |                                                                                                                                                                                                                                                                                                                                        |
|----------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Ask for permission/<br/>Assess preferences for<br/>information sharing</b>    | <ul style="list-style-type: none"> <li>• Ask patients and caregivers if they want more information on expected disease course or prognosis [36, 43]</li> <li>• Ask how (how much, when, with whom) they want information to be shared</li> </ul>                                                                                       |
| <b>Share expected disease<br/>course and prognosis</b>                           | <ul style="list-style-type: none"> <li>• Explain expected symptoms and functional decline, and timeline [44]</li> <li>• Acknowledge uncertainty, with incremental repeated disclosure as disease unfolds</li> </ul>                                                                                                                    |
| <b>Normalize experiences</b>                                                     | <ul style="list-style-type: none"> <li>• Validate that behavioral challenges and caregiver frustrations can be common experiences while offering strategies/best practices</li> </ul>                                                                                                                                                  |
| <b>Shift focus of management<br/>as disease progresses</b>                       | <ul style="list-style-type: none"> <li>• Address deprescribing and optimize medication benefit [37, 45]</li> <li>• Customize preventative care, including screening, depending on time to benefit and goals [46, 47]</li> </ul>                                                                                                        |
| <b>Provide opportunities for<br/>caregivers to speak<br/>without PWD present</b> | <ul style="list-style-type: none"> <li>• Caregivers may prefer to speak openly about prognosis and worries away from PWD</li> <li>• Consider dementia-capable models of care that support and augment an on-going and trusted relationship between the dyads and the health care team (Care Ecosystem, UCLA, etc.) [21, 48]</li> </ul> |
| <b>Help with ACP</b>                                                             | <ul style="list-style-type: none"> <li>• Encourage all team members (SW, RN, NP/PA, MD) to have advance care planning conversations with patients/caregivers and assist with completion of documents</li> </ul>                                                                                                                        |

Shafir A. J Alzheimers Dis. 2022;86(2):787-800.

# In-Visit Roadmap for Clinical Care



Harrison KL, Boyd N, Ritchie CS. A roadmap for implementing geriatric neuropalliative care for dementia. Under review.

# Infrastructure needs



Harrison KL, Boyd N, Ritchie CS. A roadmap for implementing geriatric neuropalliative care for dementia. Under review.

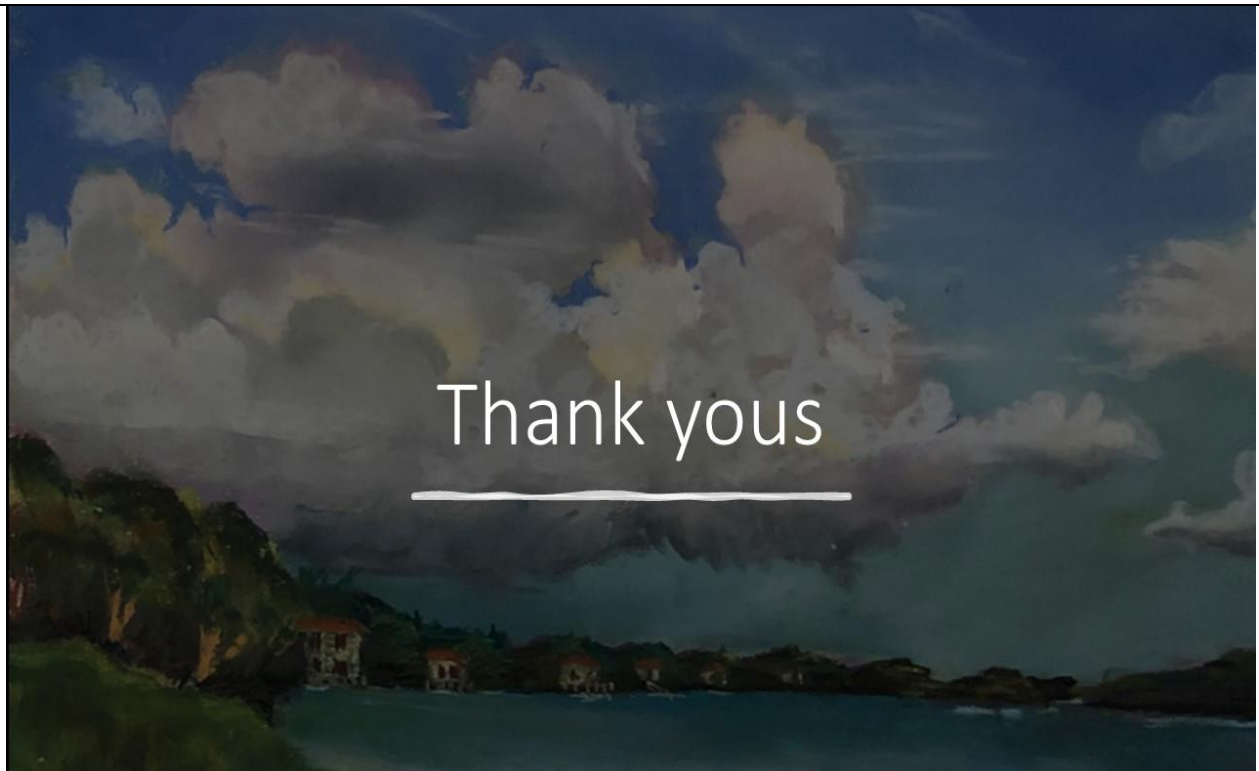
## SUMMARY

- Care gaps are numerous in dementia care
- Diagnosis and disclosure need to be approached with care and sensitivity
- Need to improve and streamline the communication between PLWD, caregivers, primary care, specialists
- A geriatric palliative care approach that keeps PLWD and caregivers at the center will be a key driver in high quality clinical care
- We need more evidence to understand what works best for PLWD and their “family of choice”



Thank you

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# Questions?

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