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Early detection. Better care.

Advance Care Planning and Legal Needs for People Living with Dementia

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UCSF

University of California San Francisco | February 21, 2023

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Financial Disclosures

- All presenters report that they have no financial disclosures.

Dementia Care Aware Program Offerings

Warmline:

A provider support and consultation service that connects primary care teams with Dementia Care Aware experts

Trainings:

- Online Trainings; *CHA training*
- Monthly Webinars
- Podcasts *forthcoming*

Interactive Case Conferences:

UCI ECHO conferences - *Sign up now!*

Practice change support:

- UCLA Alzheimer's and Dementia Care program
- Alzheimer's Association Health Systems

dementiacareaware.org **DCA@ucsf.edu**

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Our Training

dementiacareaware.org

Dashboard Admin News

Welcome to Dementia Care Aware

Welcome!

Welcome to the Dementia Care Aware (DCA) learning management system. This site provides access to the training modules for the DCA program. When you registered, you were automatically enrolled in the "*Dementia Care Aware: The Basics*" course. Select Start in the "Dementia Care Aware: The Basics" block below to begin.

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Refresher
The Cognitive Health Assessment (CHA)

1. Take the patient's history.
2. Use tools to assess for cognitive and functional decline.
3. Establish and document a patient's support person and/or health care agent.

Introduction

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Learning Objectives

At the end of this training, you will be able to:

- Define the purpose and components of advance care planning for patients living with dementia (PLWD) following the CHA
- Name three kinds of legal decision supporters older patients commonly need
- Initiate a conversation about advance care planning and provide resources

What is Advance Care Planning (ACP)?

Michelle Panlilio, DNP, GNP-BC

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Case: Mrs. Chase

Mrs. Chase is an 82-year-old woman diagnosed with Alzheimer's dementia. She has a history of wandering and becoming distressed when she forgets where she is. She lives at home with Miriam, who is her primary caregiver and IHSS worker. They live in an apartment and do not have other family to assist.

Mrs. Chase has had 16 (brief) hospitalizations and emergency room visits in the past 6 months, primarily for recurrent urinary tract infections and dehydration. Miriam verbalizes significant caregiver distress and states that her mother has had a significant decline both cognitively and physically. Miriam states her wishes for her mother's health to improve and to "get better".

What is Advance Care Planning?

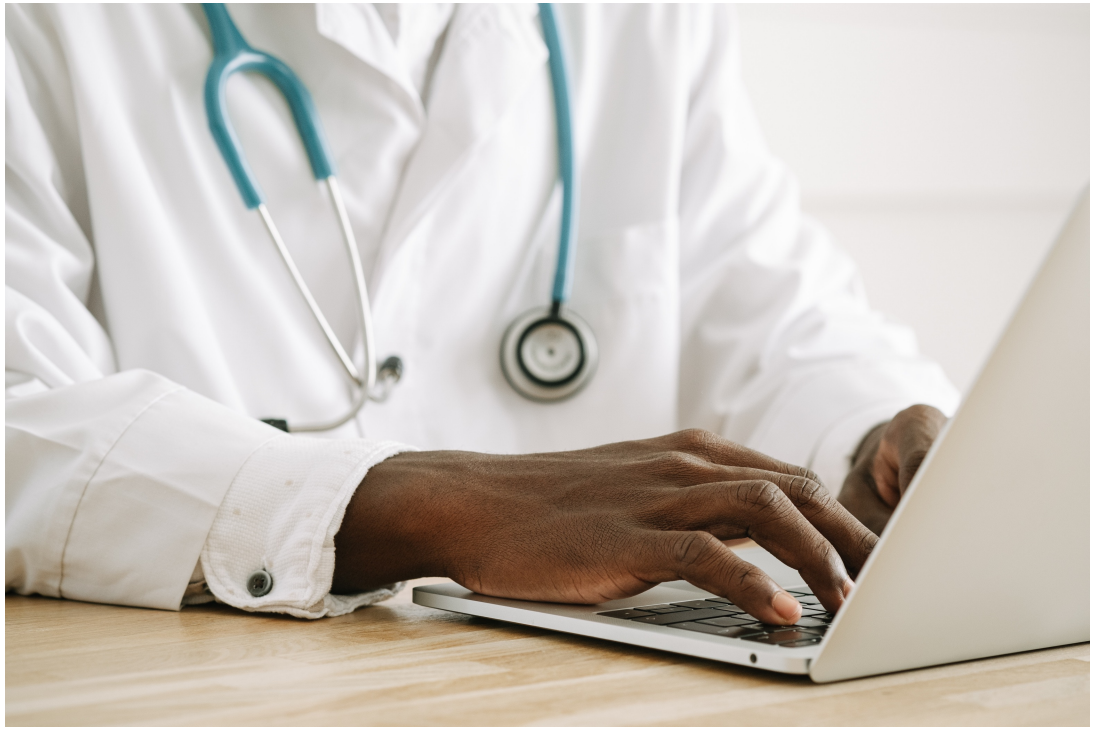
- A **discussion** between a patient, family, and clinicians to foster understanding about illness and prognosis to clarify treatment preferences, identify a surrogate, and develop goals for care in serious illness and near the end of life.
- Goal is to achieve an outcome that is best suited to the patient and the family and fits within medical standards of care

Purpose of Advance Care Planning

- Provides families and caregivers guidance (roadmap) on how to make care decisions with and for their loved one
- Assists families with honoring their loved one's wishes
- For families with conflicting goals of care, having assigned medical and financial decision makers may be helpful in providing care
- Prevent unnecessary and unwanted medical treatment and support access to needed care

Components of Advance Care Planning

A. Goals of care discussion
B. Advance directive for health care
C. Information and referral about financial and legal planning



A. Advance Directive for Health Care

Official legal document that allows a person to express values and wishes for medical care they may need during life after they lose capacity to express those values for themselves.

A. Advance Directive for Health Care (*continued)*

- Health Care Power of Attorney (part of Advance Directive or separate)
  - Designated primary, secondary, and tertiary health care decision makers
  - Defined as a person who speaks for you and makes medical decisions for you ***in case you are not able to make them yourself***
- Goals of Care and/or Resuscitation status
  - Allows the patient to choose whether or not they would like to have life-saving treatment or interventions (CPR/intubation)
  - May include patient's preference for artificial nutrition or hydration (feeding tubes)

B. Goals of Care Discussion

- Objective is to develop goals for care in serious illness and near the end of life.
- Examples of Goals of Care:
  - Avoid hospitalizations
  - Stay at home
  - Be surrounded by family
  - Avoid medical procedures
  - Prioritize patient comfort
  - Avoid pain

Formal and Informal Discussions on Advance Care Planning

What if the patient does not have or is not able to get Advance Directives for health care?

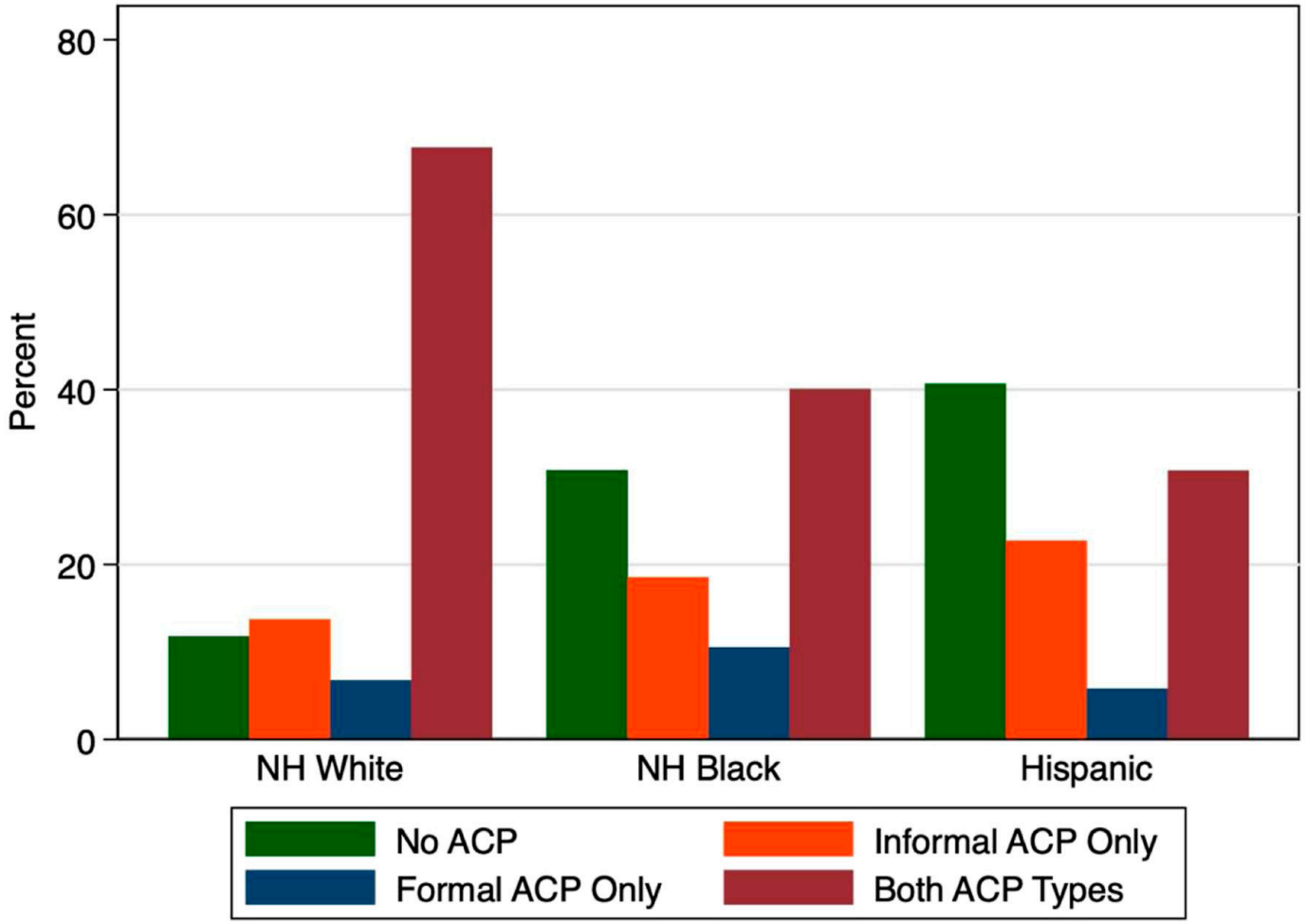


Figure 1. Distribution of advance care planning types within racial and ethnic groups.
Note. $\chi 2$ test $p < .001$. ACP indicates advance care planning; NH, non-Hispanic.

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Lenko R, et al. Racial and Ethnic Differences in Informal and Formal Advance Care Planning Among U.S. Older Adults. *J Aging Health*. 2022

Back to Mrs. Chase…

Does Mrs. Chase need Advance Care Planning?

Does her PCP/medical team need to have a goals of care discussion with the patient and her family?

Financial Decision Makers

Sarah Hooper, JD

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Case continued

Let's say no planning or actions are taken on Mrs. Chase's long-term care needs.

A month later, Mrs. Chase is taken to the hospital by police after they found her at a bus stop a block from her home. She was in her bathrobe with no shoes, crying, and asking for help, but unable to say where she lived. She is dehydrated and delirious.

Case (continued)

Miriam is on her way to the hospital and extremely upset. She says she left for just 20 minutes to get milk from a neighbor and when she came back, her mother was gone. She says "What do I do? I can't just lock her up in her own house."

The hospital discharge team thinks she needs to be placed in a facility. They have contacted a local assisted living facility that advertises they provide memory care. The facility has available beds, but will refuse to admit her until they have a financially responsible party who is able to sign her in.

Mrs. Chase never named Miriam (or anyone else) as a financial agent.

Are Long-Term Care Decisions Medical Decisions?

- Long-term care decision= health + finances
- Medicaid pays 54% of LTSS in the US
- Assisted Living NOT covered by Medicare
- Medi-Cal Assisted Living Waiver MIGHT
    - Not available in every county

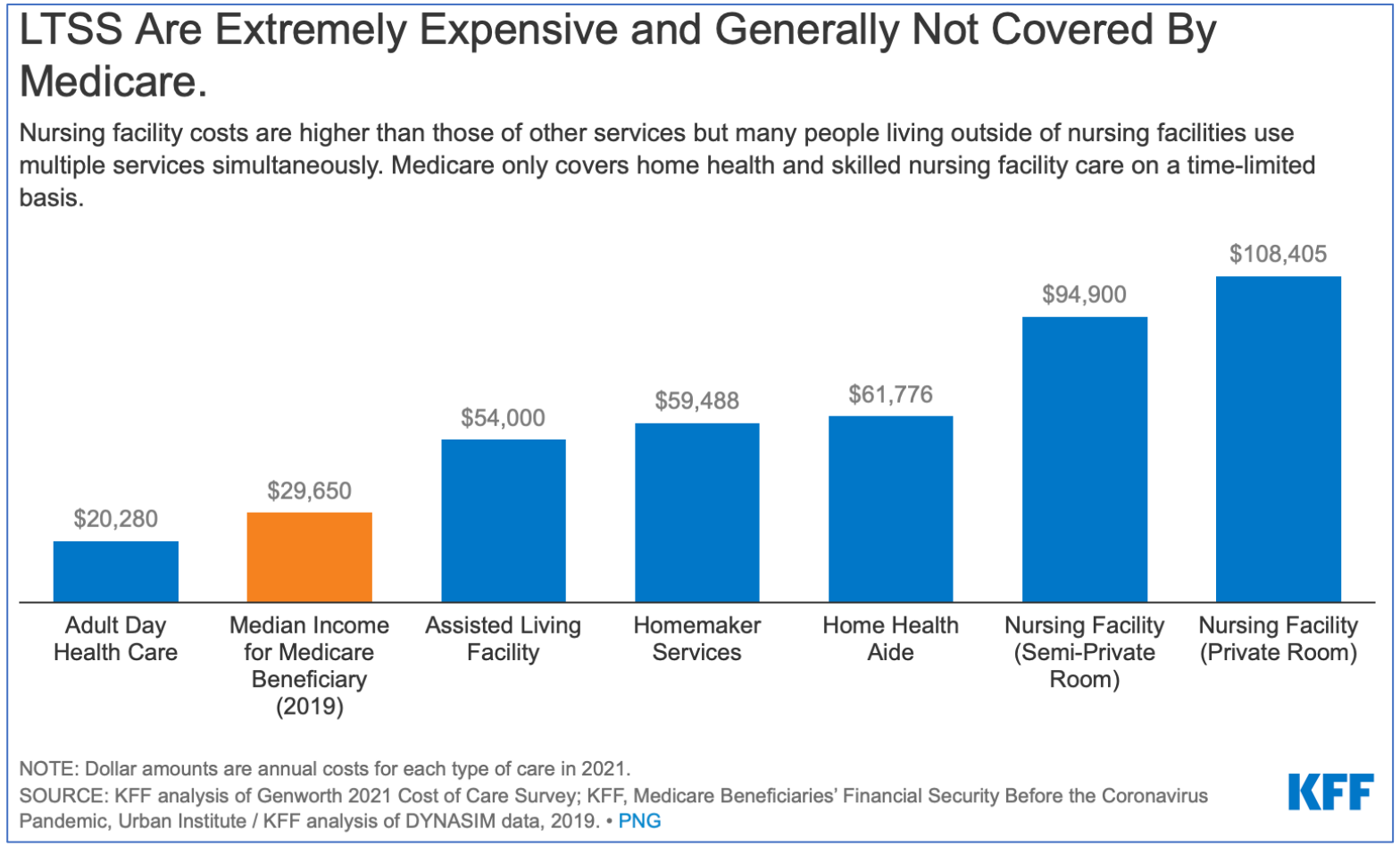

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Figure: Chidambaram and Burns. 10 Things About Long-Term Services and Supports (LTSS). Kaiser Family Foundation. Sep 15, 2022.

Who Can Make Long-Term Care Decisions?

- Patient
- Patient with formal or informal support
    - Supporter under Supported Decision-Making Agreement (new in CA)
- Person/s with appropriate legal authority
    - Health Care DPOA (Advance Directive) not enough
    - Need financial access, management, or decision-making authority

Legally-Recognized Financial Caregivers

Agent in a Durable Power of Attorney for Finances

Representative Payee

VA Fiduciary

Trustee in Living Trust

Conservator

What About Conservatorship?

- Multiple types in CA
- Probate Conservatorship = court process to establish surrogate decision maker (conservator)
- Can be initiated by any “interested person”

See CA Probate Code §1400 et seq.

What About Conservatorship?

- Legal standard is high – removing civil rights
    - Prove by clear and convincing evidence:
        - Unable to provide properly for personal needs for physical health, food, clothing, or shelter, ***and/or***
        - Substantially unable to manage financial resources or resist fraud or undue influence
- Must be least restrictive option available or tried

See CA Probate Code §1400 et seq.

Will Conservatorship Solve the Problem?

- Conservator or Public Guardian is:
  - A substitute decision maker
  - Working with the same resources and assets a patient came in with (or less)

- Conservator or Public Guardian is NOT:
  - Able to force *facilities* to take patients
  - Able to create beds/housing in a community where they don't exist
  - 24/7 caregivers

Low-Income Older Adults Don't Access Legal Help, Mostly Due to a Lack of Legal Literacy

- 70% of low-income older adults reported at least one civil legal problem in 2021
- 91% of problems did not receive any or enough legal help
- Most common unmet problems:
  - Consumer issues (43%)
  - Health (37%)
  - Income (29%)
- Most cited barriers to legal help related to lack of knowledge about legal issue or where to go for help

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Legal Services Corporation. Justice Gap Reports 2017 and 2022. Available at https://justicegap.lsc.gov/the-report/

Clinicians' Role in Financial/Legal Planning

- Help us close the knowledge gap
- Recognized as part of quality dementia care by CMS (see Clinical Recommendation Statements in MIPS High-Priority Quality Metrics for Dementia :
  - "Following a diagnosis of dementia, health and social care professionals should....provide....
    - The signs and symptoms of dementia
    - The course and prognosis of the condition
    - Treatments
    - Local care and support services
    - Support groups
    - Sources of financial and legal advice, and advocacy
    - Medico-legal issues, including driving
    - Local information sources, including libraries and voluntary organizations."

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See e.g. CMS MIPS CQM#288: Dementia: Education and Support of Caregivers for Patients with Dementia: https://qpp.cms.gov/docs/QPP_quality_measure_specifications/CQM-Measures/2022_Measure_288_MIPSCQM.pdf

Having the Advance Care Planning Conversation

Kathryn Eubank, MD

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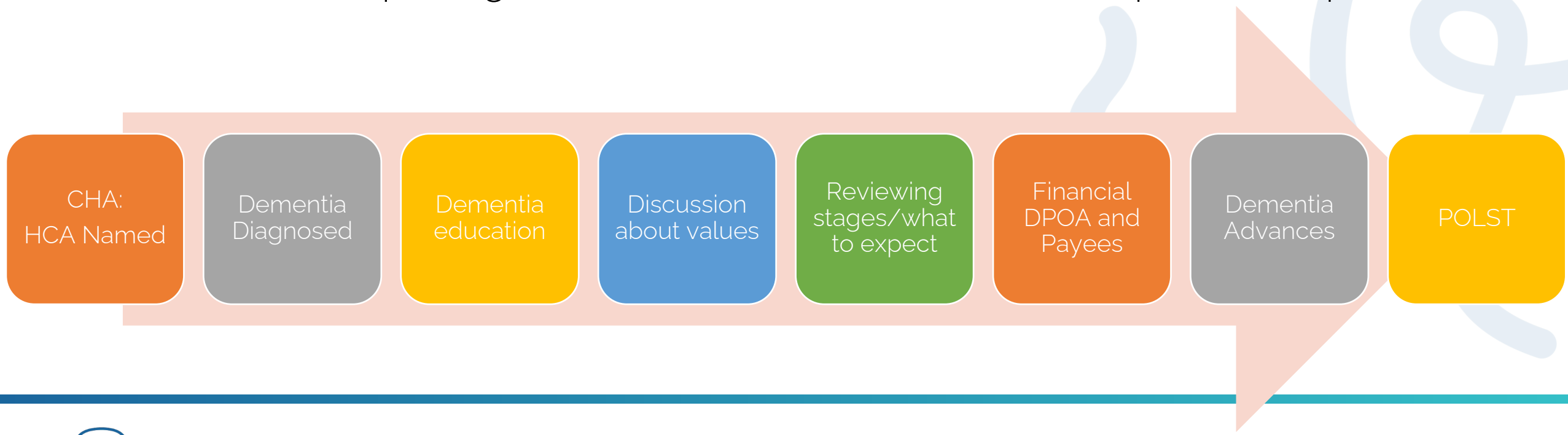
Advance Care Planning (ACP)
Things to keep in mind

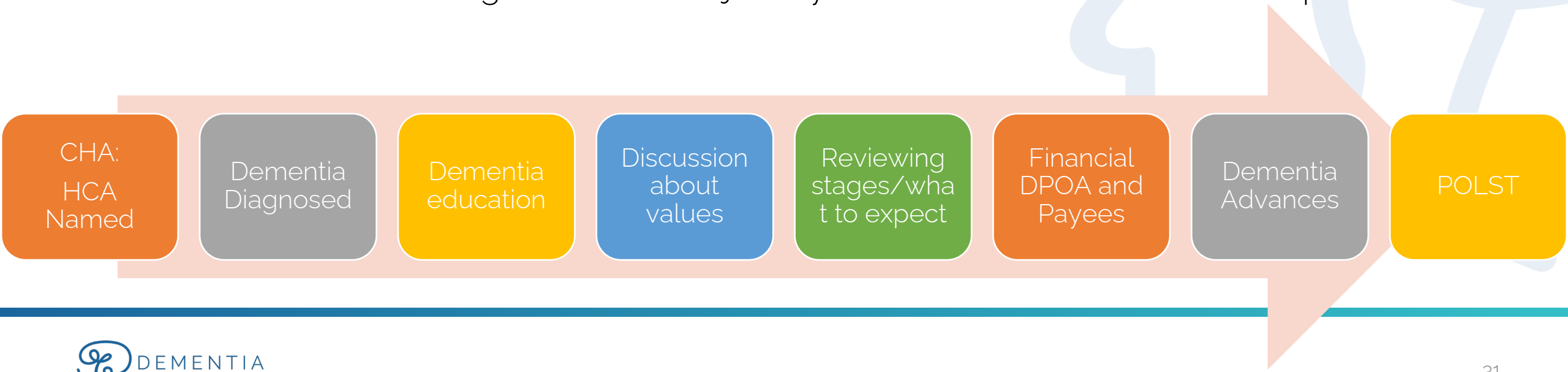
- Patients want to participate in ACP
  - In studies of patients with dementia and their caregivers, the majority report:
    - They would have preferred conversations started sooner
    - That completing assessments of their values was a positive experience



Advance Care Planning (continued)

More things to keep in mind

- Knowledge of the disease process is necessary for good decision making
- ACP is best seen as a series of conversations
  - All ACP does not need to take place in one visit, or by one member of the health care team
  - Both formal (naming specific people, completing forms) and informal ACP (recording values) is beneficial
  - Discuss preferences with the patient separately, as well as in the patient-caregiver dyad
  - Review the ACP through the illness trajectory to assure it continues to reflect patient wishes



Advance Care Planning

Initiating the Conversation

Ask permission:

- “It is important to us, as your care team, to know what values you hold most dear. Can we talk about that today?”
- “I wanted to talk with you a little today about making plans for the future. Is that OK?”
- “We want to care for you the way that best fits with your values. To do that, it is helpful to think ahead to how life may look for you several years from now. Can we plan time for that during your next visit?
- “Can I share with you some resources about dementia and planning for the future?”

Advance Care Planning

Start with open-ended questions

- “What do you understand about your diagnosis?”
- “At this time in life, what values do you hold most dear (what things are you finding meaningful and important)? Is it family, friends, hobbies, etc?”
- ”I’d love to hear more about how you think about your care and what we should consider when caring for you in the future.” (can include cultural, religious, social preferences in care as well)

Advance Care Planning

Start with open-ended questions (*continued)*

- "Who are the people in your life that you have been able to rely on the most for support during this illness? What does that support look like for you?"
- "Have you ever experienced a family member or close friend with a serious illness? What was that like? What went well, what didn't? "
- "How would you like to be looked after when you are nearing the end of your life (or, if you became very ill)?"

Advance Care Planning

Getting specific

- “Have you ever completed an advance directive?”
- “If you were in a situation where you could not speak for yourself, is there someone you would trust to make decisions about your care?”
  - Why did you choose that person?
  - Are there circumstances where you wouldn’t trust that person to make decisions for you?

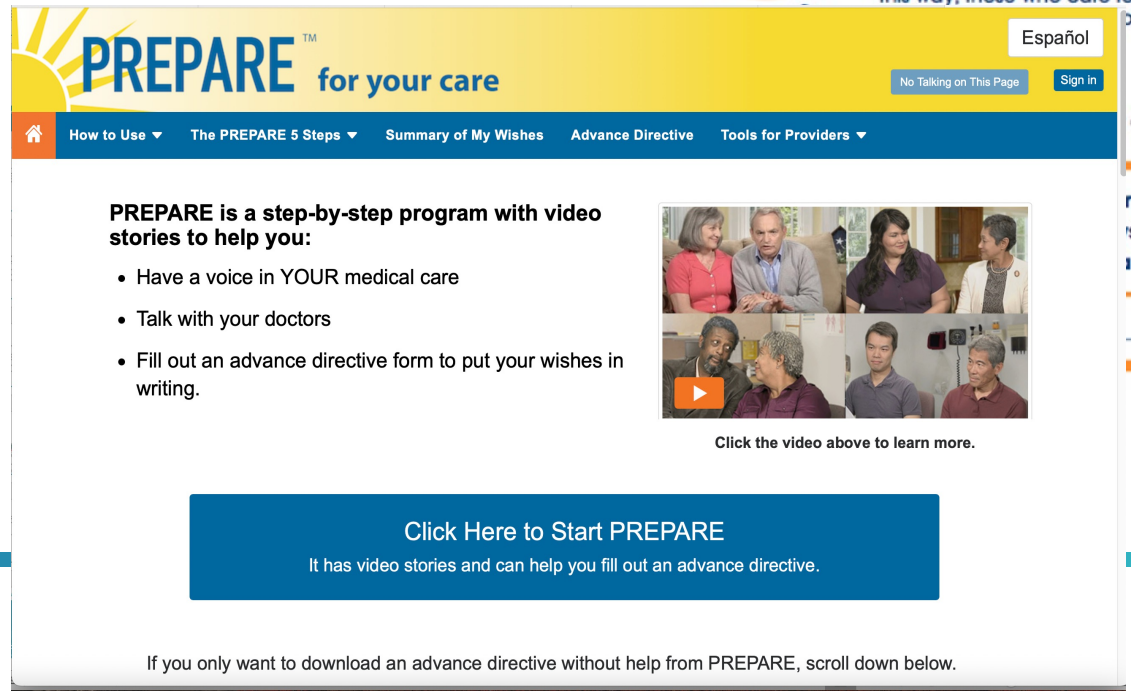
Advance Care Planning

Getting specific (*continued*)

- "As dementia worsens, it is helpful to have someone you can trust help you with tasks, such as paying bills or managing your money. Is there someone you would trust with that?"
  - Why did you choose that person?
  - Are there situations where you would worry about that person making decisions for you?
  - Have you ever written this down in a legal form?
- "Here are several items that people have said they value as their illness worsens – how would YOU rank these?"
  - Being as comfortable as possible, living as long as possible, recognizing my family and friends, staying or dying at home, being able to see "x", etc,

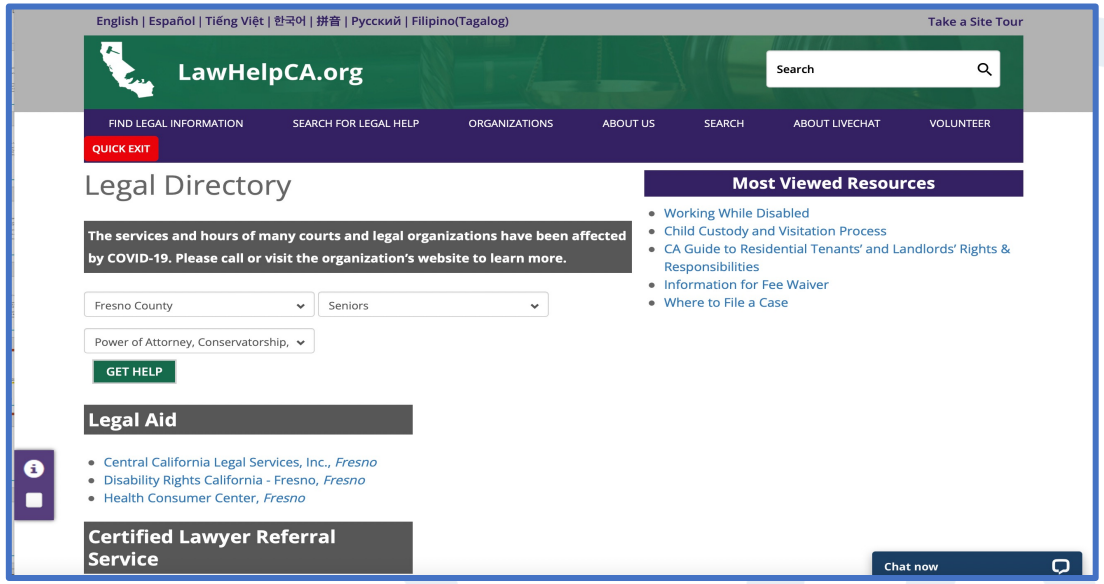
Advance Care Planning
Resources

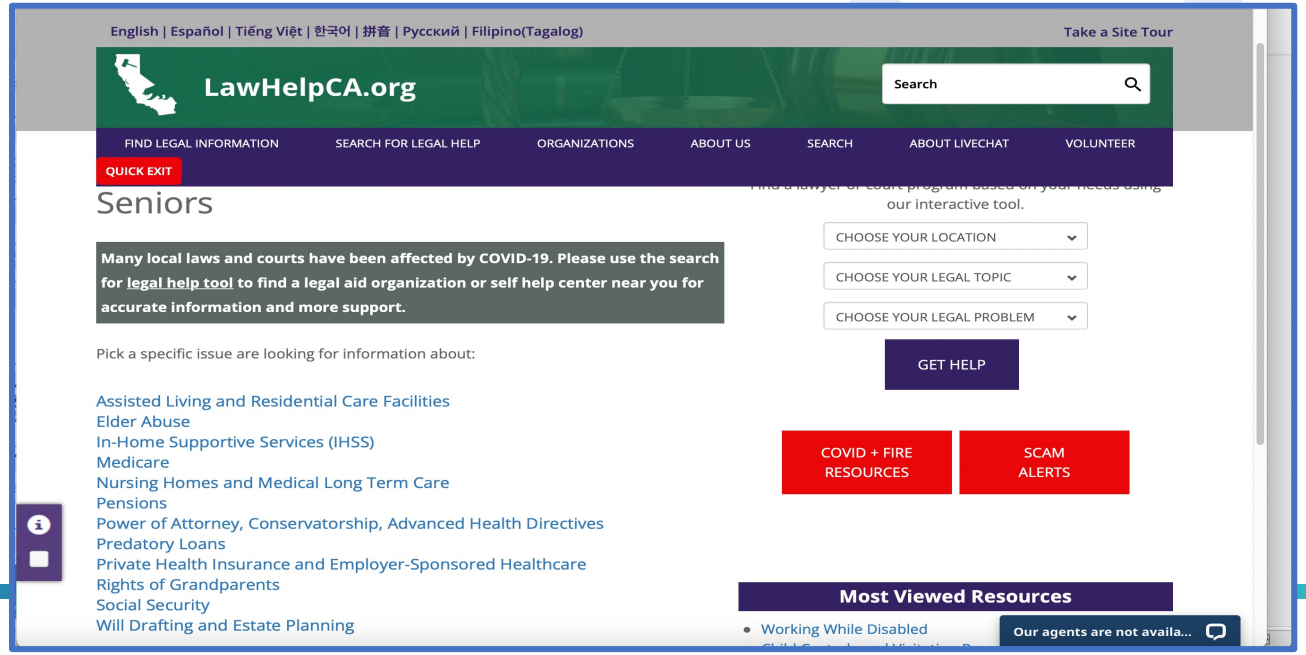
- PREPAREforyourcare.org
  - Videos for independent patient use
  - Videos for use in ACP in clinic
  - Training resources for staff
  - Advance directives forms
  - Aid in completing and printing an AD



Advance Care Planning
Resources

- LawHelpCA.org
  - DPOA for finances
  - Forms for advance directives
  - Legal information about many senior issues
  - Connecting patient to legal information and resources





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Advance Care Planning: Key Points

- The purpose of ACP is to understand and document a patient's values, preferences, and goals pertaining to their future care and document surrogate decision makers
- 3 kinds of decision support that older patients commonly need
  - Healthcare Agent
  - Financial DPOA
  - VA Fiduciary or Rep Payee
- Free planning resources available to patients, caregivers, and clinicians
  - www.PREPAREforyourcare.org
  - www.LawHelpCA.org

Additional Medical-Legal Training Available

Topics Include:

- Advance Care Planning
- Planning Needs and Considerations of Immigrant Patients
- Capacity
- Housing
- Paid Family Leave for Caregivers
- Medi-Cal and Long-Term Care
- Elder Abuse & Neglect
- Conservatorship
- How to Fill Out Disability Forms
- Income Supports/Relieving Economic Burden for Patients
- Understanding Legal and Other Community Resources for Older Patients & Caregivers

Contact us to schedule training/s for your team.

Q&A

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Have more questions? Get answers through our Warmline Support Page!

Here are some examples!

What do I prioritize after a positive cognitive health assessment?

Is the cognitive health assessment covered for patients over 65 who have Medicare but not Medi-Cal?

Can I use the cognitive health assessment with a patient with limited literacy?

Open your phone camera and scan the QR code to submit questions:

Or visit: www.dementiacareaware.org

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How to Claim Continuing Medical Education (CME) Credit?

Step 1. Please complete our evaluation survey using the link provided in the chat and a follow-up email after the webinar. For this activity, we provide CME and California Association of Marriage and Family Therapists (CAMFT) credits. Please select the correct link based on the credit type you are claiming.

Step 2. Upon completing the evaluation survey, please scan a QR code or link to claim credit:

- Use your phone camera to scan a QR code and tap the notification to open the link associated with the CME portal.
- Enter you first name, last name, profession, and claim **1 CE credit** for the webinar.

Thank You

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