



**Alzheimer's  
LOS ANGELES**

# **How to Support Your Patients Living With Dementia**

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**L.A. Care Geriatric Care Conference In Collaboration with Alzheimer's Los Angeles  
March 29, 2025, Hilton San Gabriel, CA**

# Financial Disclosures

The following CME planners and CME faculty do not have relevant financial relationships with ineligible companies in the past 24 months.

- Leilanie Mercurio, Provider Continuing Education (PCE) Program Manager, L.A. Care Health Plan, CME Planner.
- Jennifer Schlesinger, MPH, CHES, Vice President, Healthcare Services & Professional Training, Alzheimer's Los Angeles, CME Planner.
- Natalie Rosemond, LCSW, Director, Healthcare Services and Professional Training, Alzheimer's Los Angeles, CME Presenter.

An ineligible company is any entity whose primary business is producing, marketing, selling, re-selling, or distributing healthcare products used by or on patients.

Commercial support was not received for this CME activity.

# About Me

- Director of Healthcare Services
- Licensed Clinical Social Worker in California
- Master of Social Work from the University of Southern California
- Prolonged and Chronic Illnesses, End-of-Life, Grief and Bereavement



# Learning Objectives

## At the conclusion of this training, learners can:

- Define **person-centered care** and its significance in dementia management.
- Describe the importance of **culturally tailored care planning** for dementia patients.
- Explain the **role of a family caregiver** in supporting a person living with dementia.
- Identify at least three (3) strategies to **support a person living with dementia** in a healthcare setting.
- Identify at least three (3) strategies to **support a family caregiver** and address their needs.

# The Monkey and the Fish

Eastern Parable  
Image by: Debbie Tomassi



# Why Is It Important to Understand Diverse Perspectives and Dementia?

## It Affects...

- How individuals and families view and deal with the disease and behaviors.
- Help to better understand interactions you have with the person living with dementia and their families.
- How we reach and support clients and families in a person-centered way.



# Person-Centered Care in Dementia

**Cultural and personal view of illness, dementia, and aging**

**Understanding behavior through a personal and cultural focused lenses**

**Person-Centered Care Planning**



# Defining Person-Centered Care

## What is Person-Centered Care?

### **Prioritizing the unique needs, preferences, and values of the individual**

- Fosters trust, encourages autonomy, and meaningful engagement.

### **Active participation from the patient and care team in decision-making**

- Importance of routine and familiarity to enhance compliance.
- Improves patient quality of life reducing behavioral symptoms.

# Benefits of Person-Centered Care

## Ethical Considerations in Dementia Care

- Autonomy vs. safety
- Decision-making capacity

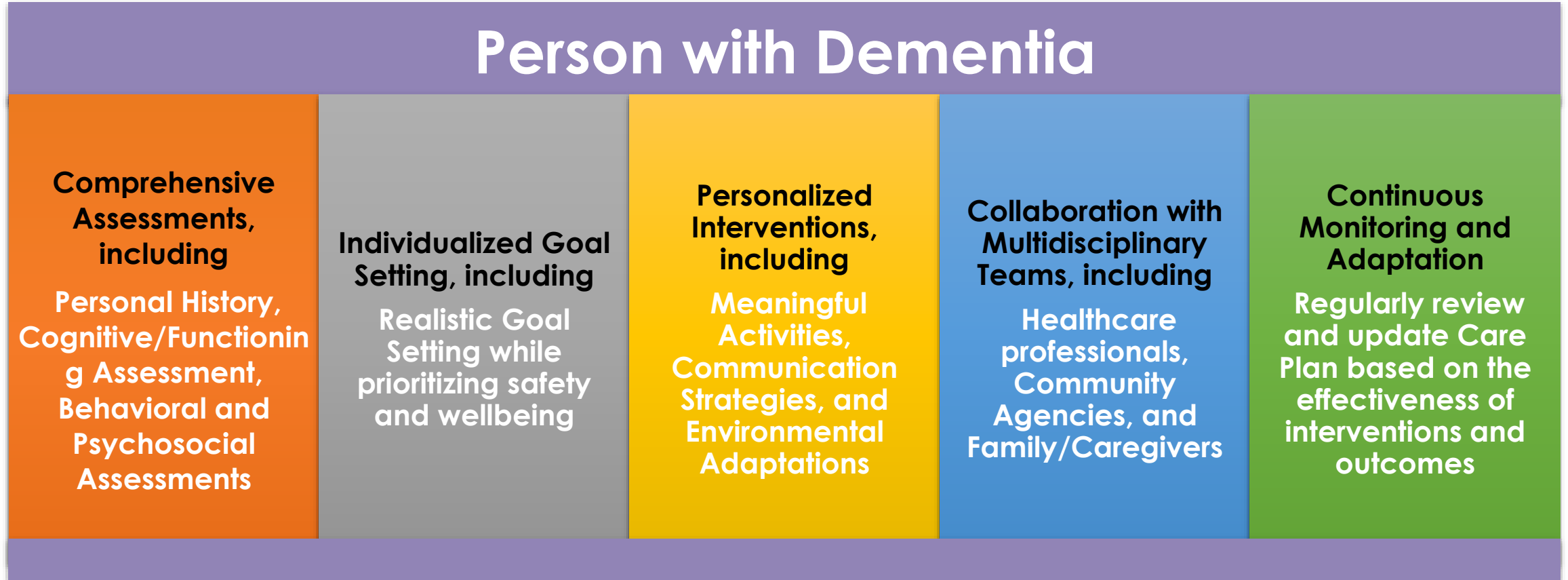


## Advanced Care Planning

- Importance of discussing end-of-life wishes.
- Legal considerations: advance directives, POLST.
- Hospice and palliative care options.

# Implementing Person-Centered Care

## Person-Centered Care in Practice:



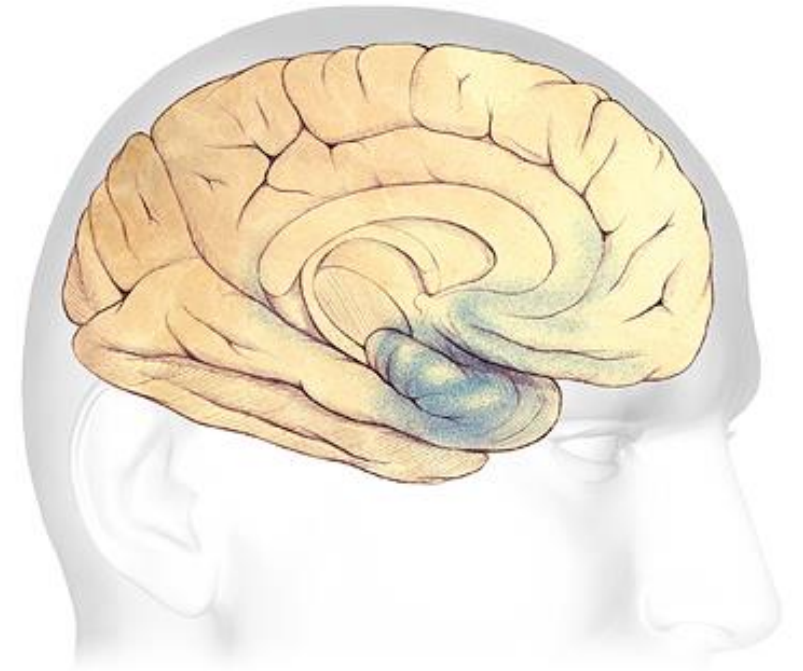
Fazio et al., 2018, Alzheimer's Association, 2022).  
Cohen-Mansfield, 2018, . Gitlin & Hodgson, 2018).



# Culturally Tailored Care Planning

# Western Views of Dementia

- Healthcare uses the biomedical model
- Dementia = medical condition of brain dysfunction
- Dementia = umbrella term for several diseases of the brain, including Alzheimer's



# Diverse Communities' Views of Dementia

- Dementia = Alzheimer's
- Cognitive issues may be expected and dismissed as normal.
- Associated with a spiritual issue, a family curse, madness, or a source of shame .



The screenshot shows the Urban Dictionary website interface. At the top, there is a search bar with the text "Type any word...". Below the search bar, there is a navigation menu with "Browse", "Vote", and "Store" options. A news banner is visible, featuring a colorful image of a person's head and the text "Doctors Say 1 Weird Compound Protects Against Dementia in New Shock Study." The main content area displays the definition for "old timer's disease". The word is highlighted in blue. Below the word, it says "slang for Alzheimer's disease". A paragraph of text follows: "The **elderly** are **not necessarily** the only **victims** of old timer's disease, although they are the ones who get it the most." Below this text are several hashtags: "#alzheimer's #all timer's disease #old-timer's disease #old timers disease #oldtimer'sdisease". At the bottom of the definition, it says "by The Return of Light Joker June 10, 2010". There are also social media sharing icons (Twitter, Facebook) and a like/dislike button showing 50 likes and 22 dislikes.

# Culturally Tailored Care Planning

## Disparities in Dementia Care

- Racial and ethnic disparities and biases in diagnosis and treatment.
- Socioeconomic barriers to care.
- Gender disparities in caregiving burden.

**Healthcare providers must recognize and mitigate biases.**

Barnes .791, 2019; Gilmore-Bykovskyi et al. 305, 2019; Mehta et al. 612, 2018; Yaffe et al. 1103, 2020; Perales-Puchalt et al.2022, Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2023*. Alzheimer's Association, 2023,

# Alzheimer's Disease in the US



**African-Americans** are 2 times as likely to have Alzheimer's/dementia as older whites

**Hispanics** are about 1 – 1.5 times more likely to have Alzheimer's/dementia, But lower diagnosis rates

**Asian-Americans** 4x more likely to carry the gene, but only account for 8% of diagnosis

**Indigenous communities** 1 in 3 Indigenous Elders will develop dementia

Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2021;17(3).



# Diversity in the Aging Population

## LGBTQ+ Community

### Prevalence and Trends

- **Increased Risk:** 29% more likely to report memory loss and confusion compared to their heterosexual counterparts .
- **Social Isolation:** Are more likely to experience isolation.

### Unique Needs

- **Stigma and Discrimination:** Concerns about encountering prejudice in care settings.
- **Legal and Financial Concerns:** May have fewer financial resources and legal protections, affecting access to quality care and support.

Flatt et al., 2018, Alzheimer's Association. "LGBTQ+ Community Dementia Resources." *Alzheimer's Association*, <https://www.alz.org/help-support/resources/alzheimers-and-dementia-resources-for-lgbtq-commun>.  
National Care Forum. "Dementia Care and LGBT Communities: A Good Practice Paper." *National Care Forum*, <https://www.nationalcareforum.org.uk/wp-content/uploads/2019/10/Dementia-care-and-LGBT-communities.pdf>.

# Culturally Tailored Care Planning

## Get to know the person *and* the family

- Culture
- Community
- Sexual orientation
- Gender identity
- Background
- Values
- Beliefs
- Linguistic needs
- Interests
- Preferences
- Decision-making processes





# Role of Caregivers

# Type of Caregiving Families

- Solitary Caregiving
- Observed Caregiving
- Tag Team Caregiving
- Uneasy Caregiving Alliance
- Collaborative Caregiving



Hepburn, K., Sherman, C. W., Lewis, M., Tornatore, J., & Dollo, J. (2019). *Savvy caregiver express* (Adapted from the University of Minnesota's Savvy Caregiver Program). Alzheimer's Los Angeles.

# Family Caregiver Beliefs

- Family roles and responsibilities
  - Care coordinator vs. decision maker
- Chosen family/factious kin
- Family history and feelings towards caregiving



# Note the Toll on Family Caregivers

- Stress
  - Denial
  - Anger
  - Social withdrawal
  - Anxiety - Irritability
  - Depression – Sleeplessness
- Adverse changes in health and well-being (health problems and mortality).



Zarit. Family Caregiving. B. Bensadon (Ed): *Psychology and Geriatrics*.



# Supporting a Person Living with Dementia

# Supporting a Person Living with Dementia

- **Pain Management:** non-verbal signs and symptoms of pain  
Massage, music, and physical movement.
- **Sleep Considerations:** Addressing sleep disturbances.
- **Emergency Department visits:** managing dementia-related emergencies /preventative care.
- **Nutrition Considerations:** Education on nutrition modification and tools available.

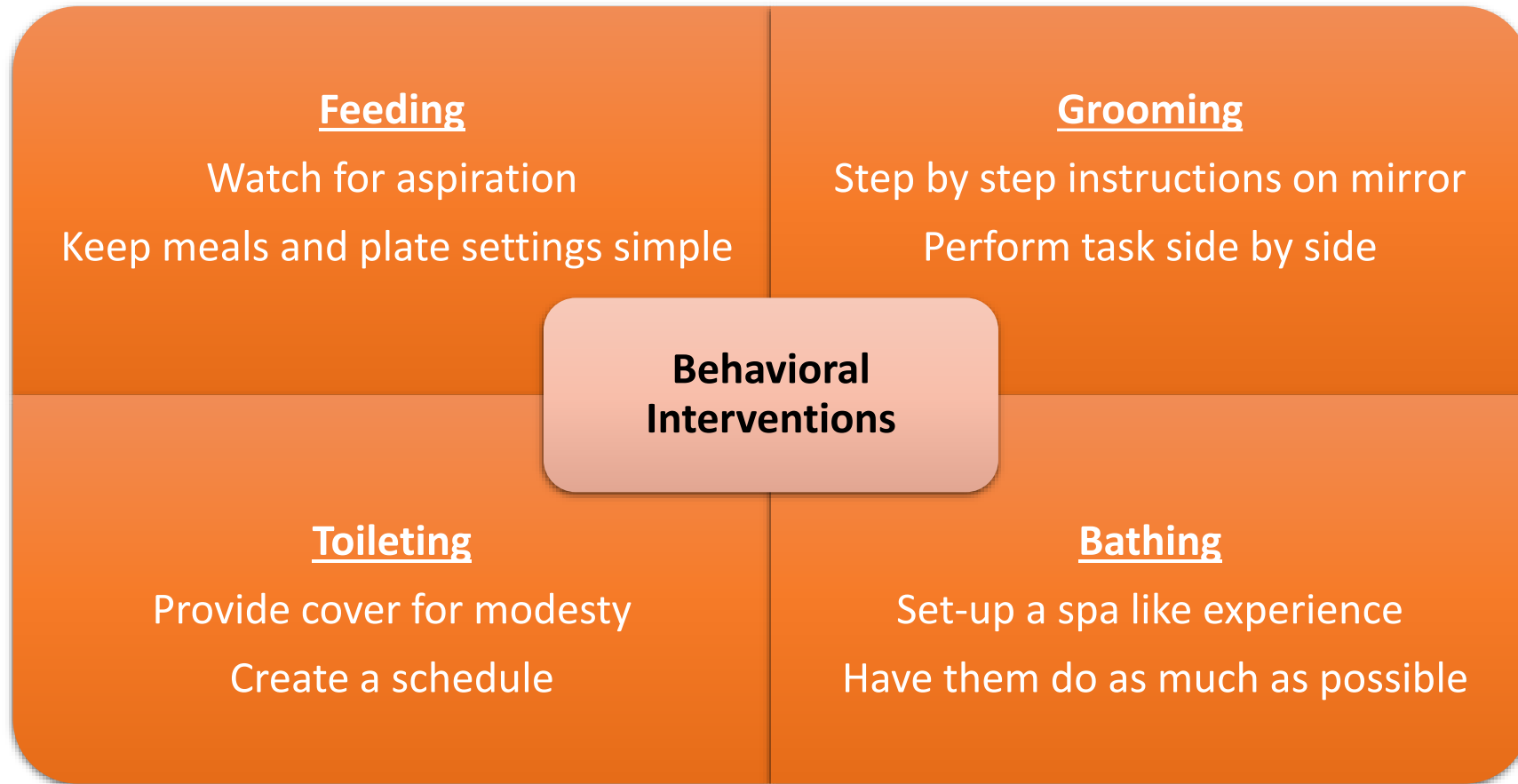


# Supporting a Person Living with Dementia: IDEA!

- **I**dentify the problem/challenging behavior
  - Identify the what, when, where, who
- **E**xplore what may be causing the behavior
  - triggers and meaning
- **A**adjust what can be done
  - Provide problem-solving strategies



# Supporting a Person Living with Dementia: IDEA!



# Feeding Adaptive Equipment



Built up Utensils

Non spill Bowls



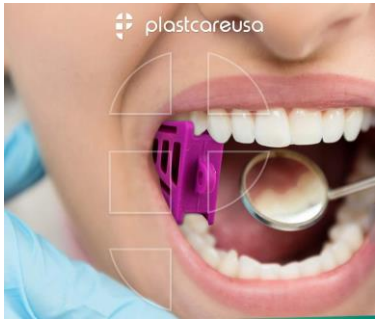
Nosey Cups

Jelly Drops



# Grooming Adaptive Equipment

“Mouth Prop”



Three Bristle Toothbrush



Instructions for mirror



Fluoride-Free Toothpaste

Soft Bristle Toothbrush



# Toileting Adaptive Equipment



Male Urinal



Female Urinal



Chux/ Bed Pad



Bed Pan



Raised Toilet Seat



Purewick

# Bathing Adaptive Equipment

## Hair Washing Options



Hair Washing Basin



Rinse Free Soap



Dry Shampoo



Rinse Free Shower Cap



# Supporting Caregivers and Addressing Needs

# Dementia Considerations

- Educate people with dementia cannot change, only caregivers can adapt.
- Normalize that role changes occur for everyone involved.
- Acknowledge caregivers' efforts and regularly assess caregiver well-being during patient visits.



*Caregiving is usually more demanding as the disease progresses*



# Addressing Challenges



## Common Problems

## What Helps

- Denial —————> Knowledge & skills
- Family dynamics —————> Partner with the family
- Lack of role flexibility —————> Talking
- Lack of experience —————> Calling community services/supports - such as Alzheimer's Los Angeles

# Strategies for Supporting the Caregivers

## Providing Carer Options

- Dementia capable homecare providers / respite
- Medi-Cal Waiver program / IHSS

## Palliative Care

- GUIDE Medicare Program

## Connecting Caregivers with Resources

- Non-profit and senior organizations
- Financial & Legal services

## Emotional and Mental Health Support

- Connect to counseling and support groups



# Incorporating CalAIM Programs

CalAIM	Enhanced Care Management	Community Based Organizations
<p>California Advancing and Innovating Medi-Cal (CalAIM) supports high-risk populations</p>	<p>Enhanced Care Management (ECM) provides coordinated care for dementia patients</p>	<p>Community based organizations (CBOs) and services help caregivers access respite care, home modifications, and nutritional assistance</p>

# Dementia Informed Approach

## *Assistive Technology: tools/apps for patients and caregivers*

- Tools:
  - LA Found
  - Bed/door alarms
  - Sensor lights
  - Automatic pill dispensers
- App Based Technology:
  - LAPD AirTag program
  - CareMobi App (clinician and family)
  - HeroGeneration (family-centered)
  - Screen Alexa
  - SMART appliances





# Frequently Asked Questions

# Frequently Asked Questions (FAQs)

## 1. What is person-centered care, and why is it important for healthcare professionals?

A. Person-centered care involves tailoring care to the individual's preferences, values, and needs. For healthcare professionals, this approach improves patient outcomes by fostering trust, enhancing compliance with treatment plans, and reducing agitation and anxiety in patients living with dementia. It emphasizes treating the person, not just the condition.

## 2. How can families access financial assistance for caregiving?

A. Families can explore options like:

- **Medi-Cal waiver programs** for in-home or long-term care services. These include In-Home Supportive Services (IHSS) and Cal AIM programs.
- **Nonprofit organizations** offering respite care grants and support.
- **Local Area Agencies on Aging (AAA)**: These agencies can connect families with community resources, caregiver support services, and financial aid options.

# Frequently Asked Questions (FAQs)

## 3. How can medical professionals recognize and address caregiver burnout?

- A. Signs of caregiver burnout include physical exhaustion, emotional overwhelm, irritability, and depression. Healthcare professionals should:
- Regularly assess caregiver well-being during patient visits.
  - Offer referrals to counseling, mental health services, or support groups, including those provided by non-profit or community organizations that specialize in dementia and know their communities.
  - Provide resources for respite care and self-care education.
  - Acknowledge caregivers' efforts and emphasize their importance in the care process.

## 4. How can healthcare professionals incorporate cultural sensitivity into care planning?

- A. Cultural sensitivity is essential for building trust and improving care outcomes. Steps include:
- **Assessment:** Ask about cultural practices, traditions, and expectations related to caregiving and medical care.
  - **Communication:** Use staff that are able to speak the language needed or use interpreters, if necessary, avoid medical jargon where possible, and try speaking plain language.
  - **Education:** Provide culturally tailored materials and explain care strategies in a way that respects the family's values.
  - **Involvement:** Include family members in discussions to honor collective decision-making, which is common in some cultures.

# Thank you



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**844.HELP.ALZ**  
**AlzheimersLA.org**

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