



Assessing and Connecting with the Caregiver

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Introduction



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Financial Disclosures

- No presenters have financial disclosures to report

Dementia Care Aware Program Offerings



Warmline:

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



Trainings:

- On-line Trainings; *CHA training*
- *Monthly Webinars*
- Podcasts *forthcoming*



Interactive Case Conferences:

UCLA and UCI ECHO conferences - *Sign up now!*



Practice change support:

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

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.



Refresher

The Cognitive Health Assessment

- 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.

Learning Objectives

- Describe two barriers to engaging family caregivers in the care of patients with cognitive impairment or dementia.
- Explain two potential benefits to engaging family caregivers in the care of patients with cognitive impairment.
- Understand the role of social workers in supporting caregivers.
- Identify effective strategies for assessing family caregiver well-being and risk of burden as a team.



Assessing and Connecting with the Caregiver

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Formal versus Informal Caregivers

Formal Caregiver – a provider associated with a formal service system. Typically paid.

Family (Informal) Caregiver – any relative, partner, or friend who provides a broad range of assistance (emotional, financial, physical) for someone with a chronic or disabling physical or cognitive condition. Typically unpaid.

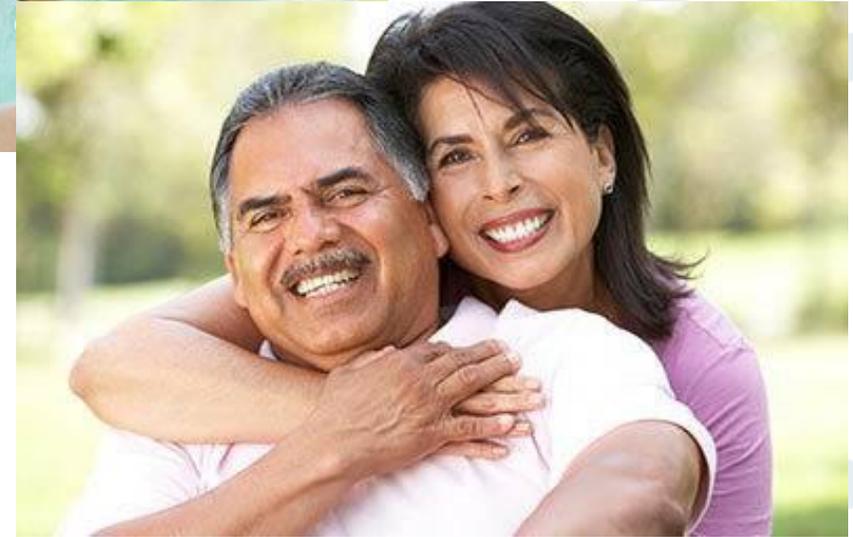
Dementia Caregiving in the US

- 80% of people with dementia are receiving care in their homes.
- Each year, more than 16 million Americans provide more than 17 billion hours of unpaid care for family and friends with dementia.
- Caregivers of people with dementia provide care for a longer duration than caregivers of people with other types of conditions



Dementia Caregiving in the US

- 2/3 of dementia caregivers are women
- 1/3 of dementia caregivers are age 65 or older
- 1/4 of dementia caregivers are “sandwich generation”



Assessing Caregivers in Health Care Setting



- Only 29% of caregivers report being asked by a healthcare professional about their caregiving needs
- Only 13% of caregivers were asked what they need to be able to care for themselves

Barriers to Reaching Out to Caregivers for Patients

- Professional code of ethics emphasizes obligation to the patient and offers little guidance in engaging their caregivers.
- Electronic health records provide limited options for identifying and tracking involved caregivers.
- Reimbursement structures focus on the patient, providing limited direct incentives for engaging their caregivers.
- Medical training focuses on individual patient treatment and management, creating a lack of provider comfort with family-centered care.

Why Engage Family Caregivers?

Ease care transitions

Overcome communication barriers

Engage patient in self-management

Improve patient outcomes

Inform disease understanding/management

Prevent adverse events



Why Engage Family Caregivers?

Caregivers at-risk for poor outcomes

Support caregiver choice to provide care



Determine caregiver ability/willingness to assume care

Help caregivers gain access to resources

Caregivers' Access to Protected Health Information

1. Personal representatives

- power of attorney, surrogate decision-maker, guardian

2. HIPAA written authorization

3. Family and friends' rule

- patient consent, patient does not object to sharing, provider determines sharing is in patient's best interest

For Providers

Develop a Plan of Care: *Seven Key Domains*

1. Context
2. Caregiver's perceptions of care recipient's health and functioning
3. Caregiver's values and preferences
4. Caregiver's well-being
5. Consequences and rewards of providing care
6. Caregiver's skills and abilities to provide needed care
7. Resources available to the caregiver

Strategies for reaching out to family caregivers

<i>Domain</i>	<i>Specific Strategies</i>
Ask strategic questions about caregiving	<ol style="list-style-type: none">1. Ask about caregivers' own health and well-being2. Recommend keeping a journal of care3. Recommend listing decision-making challenges that can be discussed in future encounters
Engage in active listening	<ol style="list-style-type: none">1. Provide reassurance2. Validate caregiver efforts3. Show empathy4. Reaffirm ethical dilemmas that caregivers experience

Strategies for reaching out to family caregivers

<i>Domain</i>	<i>Specific Strategies</i>
Offer resources	<ol style="list-style-type: none">1. Provide ongoing education on patient disease2. Recommend caregivers talk with their own physician3. Refer caregivers to specialists (e.g. counselor) as needed4. Refer caregivers to support groups and information
Prepare office and staff	<ol style="list-style-type: none">1. Integrate family education & support in office practices2. Ask if a patient receives help from a family member as part of medical history taking3. Ask the family member what care responsibilities he or she has and how he or she is doing4. Provide education to office staff about caregiving5. Develop office protocol that recognizes and includes caregiver as part of the medical encounter

Caregiver Burden

- 32% of caregivers nationally experience burden
- 63% are at increased risk of caregiver mortality
- Caregivers experience worse depression and anxiety, poor self-care
- They have worse patient physical and mental health outcomes



Risk Factors for Caregiver Burden

<i>Domain</i>	<i>Risk Factor</i>
Caregiver demographics	women, spouse, low education, unemployed
Caregiver psychosocial	depression, anxiety, lack of coping skills, social isolation
Caregiving context	longer duration, greater # of caregiving hours, financial stress, lack of choice, co-residing, medical/nursing tasks
Care recipient	mental health issues, dementia, long-term physical condition

Catalysts for Discussing Caregiver Burden with Patients' Caregivers

Caregiver Health	1. To provide the very best patient care, I find I need to also pay attention to my patients' caregivers. Can you tell me a bit about how you are feeling/doing?
Quality of Life	1. I know that many family caregivers find the role to be very stressful. How are you coping with these responsibilities?
Support	<ol style="list-style-type: none">1. Many caregivers don't want to burden others. Are there times when you really need help but don't ask for fear of being a burden?2. Who gives you support? How helpful is this support?3. Caregiving is a very hard job and the best way to do it well is to take advantage of some of the resources available for help. May I help you with a referral?

Caregiver Burden Assessment Tools

- 35 general and 19 disease specific (mostly for dementia) instruments.
- Lacking culturally and linguistically tailored instruments.



Zarit Burden Short Form (ZBI-4)

1) Do you feel that because of your relative that you don't have enough time for yourself?

2) Do you feel stressed between caring for your relative and trying to meet other responsibilities (work, home)?

3) Do you feel strained when you are around your relative?

4) Do you feel uncertain about what to do about your relative?

0=Never; 1=Rarely; 2=Sometimes; 3=Quite Frequently; 4=Nearly Always

***Total 1-4 (maximum score = 16); Score of 8 indicates high burden**

Bédard M, et al. The Zarit Burden Interview: a new short version and screening version. Gerontologist. 2001 Oct;41(5):652-7. doi: 10.1093/geront/41.5.652. PMID: 11574710.



Social Work: Assessing and Connecting with the Caregiver

Joseph Herrera, MSW, ASW

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Social Worker as a Support in Dementia Care

- Assist primary care provider (PCP) in navigating the relationship with the patient and caregiver.
- Source of support for individuals and families living with dementia.
- Must be knowledgeable about dementia, laws, resources available, and how to navigate systems.
- Medical practices need a workforce in social work that is dementia-competent to support patients and caregivers doing dementia care.



Role of the Social Worker

Primary focus of the relationship is the caregiver



Social Workers are the link between medical services and the community

- Care planning: immediate and long term
 - Care team (the person's support system)
 - Financial
 - Medical insurance
 - Legal (wills, trusts, conservatorship)
 - California Family Rights Leave (CFRA) /California Family Leave Act (FMLA)
- Provide direct patient and caregiver care
 - Short term
 - Periodic crisis
 - Address evolving needs
- Supportive counseling
 - Self care
 - Direction
 - Needs
- Re-assessment of needs on regular basis

Preparing the patient's care team for follow-up visits

- Ongoing list of concerns
- Changes in patient (memory, mood, function, medical)
 - Date of onset
 - What triggered the change
- General health for other medical issues
- What are the caregiver's expectations of the visit
- Bring a list of current medications (prescribed and over-the-counter)
- Ask questions and for clarification
- Current health concerns of the caregiver (any chronic illness present)
- Take notes/make time to take notes



Interventions to Support Caregivers and Patients

- Psychoeducational interventions for dementia caregivers modestly effective
- Pharmacologic interventions can reduce caregiver burden
- Studies show improvements in symptoms associated with caregiver burden (e.g., mood, coping, self-efficacy)



Practical Interventions to Target Caregiver Burden

- Involve caregivers as members of health care team
- Encourage self-care
- Provide education and information (e.g. support groups, caregiving organizations)
- Use the support of technology (e.g. patient portals)
- Coordinate/refer for assistance with care (e.g. home health, meal delivery services, transportation)
- Respite care (e.g. hospice, adult day programs)



Incorporating social workers in your practice

Supporting caregivers improves outcomes, so... food for thought.



- Do you have social workers?
- Are they part of your interprofessional team?
- Are they trained to work with dementia patients and caregivers?
- Can you identify social workers in your area to collaborate with your practice?

Resources for Caregivers: Sample list

- Alzheimer's Association
- Alzheimer's Organizations: Alzheimer's LA, Alzheimer's OC, Alzheimer's SD
- Family Caregiver Alliance
- California's Caregiver Resource Centers
- Models of Care: Care Ecosystem
- Well Spouse Association
- The Caregiver Action Network
- Aging Care
- Eldercare Locator

Take Home Points

- Caregiving is of increasing importance to an aging population of patients with physical and cognitive disabilities.
- Engaging caregivers is ethical and beneficial to providing high quality patient care.
- Social workers with competency in dementia care and resources can be key to supporting caregivers.
- Practical strategies can be employed to effectively support caregivers in caring for patients.



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

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.

Link to CME evaluation survey: https://ucsf.co1.qualtrics.com/jfe/form/SV_3mWojYXD1O3i8F8

Link to CAMFT evaluation survey: https://ucsf.co1.qualtrics.com/jfe/form/SV_aauUtXgjNzcyXoW

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



Resources for Caregivers

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- [Family Caregiver Alliance](#)
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