

Behavioral Symptoms in Dementia, Part 1: Assessment and Initial Care Plan

Presenter: Michelle Panlilio, DNP, GNP-BC
Moderator: Anna Chodos, MD, MPH



Introduction



Michelle Panlilio, DNP, GNP-BC

National Lead Dementia Care Specialist, UCLA
Alzheimer's and Dementia Care Program



Anna Chodos, MD, MPH

Primary Care & Geriatrics
Associate Professor, UCSF Department of Medicine
Executive Director, Dementia Care Aware

Financial Disclosures

- All presenters report no financial disclosures.

Dementia Care Aware Program offerings



Warmline:

1-800-933-1789

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



Trainings:

- Online Trainings
- Live Cognitive Health Assessment (CHA) trainings
- Monthly webinars
- "Dementia Care on Air" Podcasts



Interactive Case Conferences:

UCLA and UCI ECHO conferences



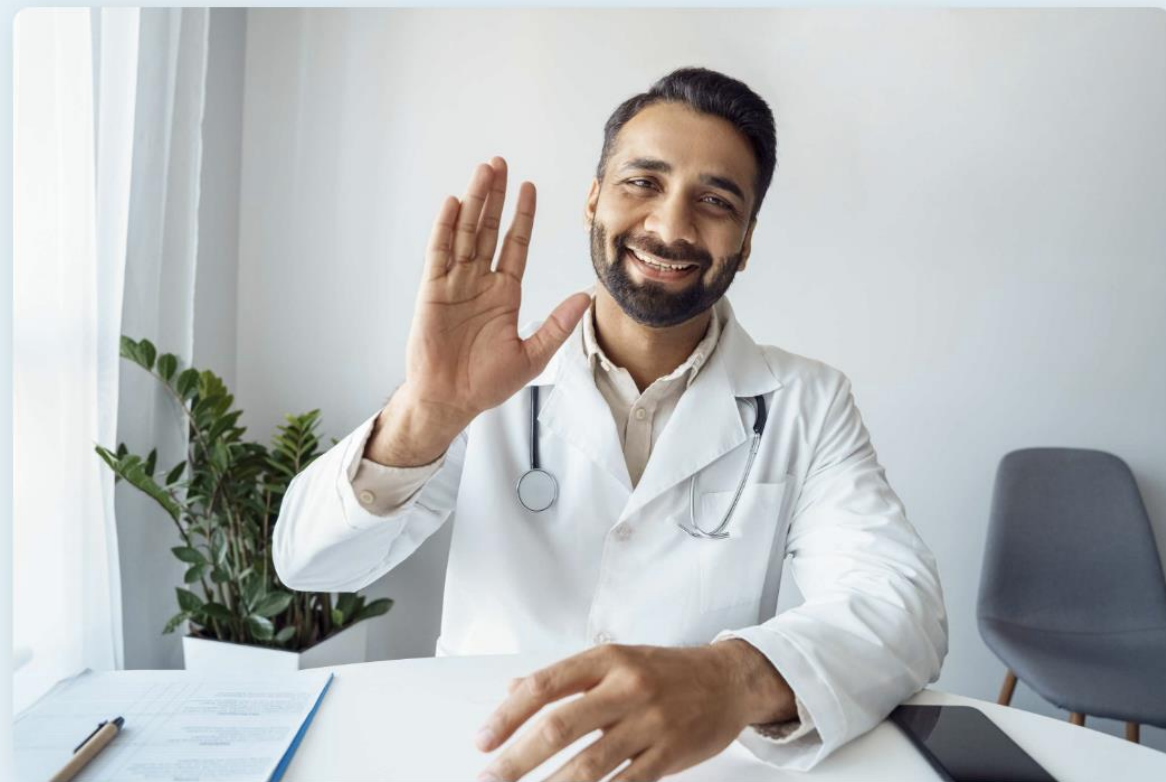
Practice change support:

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

Our Training

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 "*The Cognitive Health Assessment: The Basics*" course. Select Start in the "The Cognitive Health Assessment: The Basics" block below to begin.



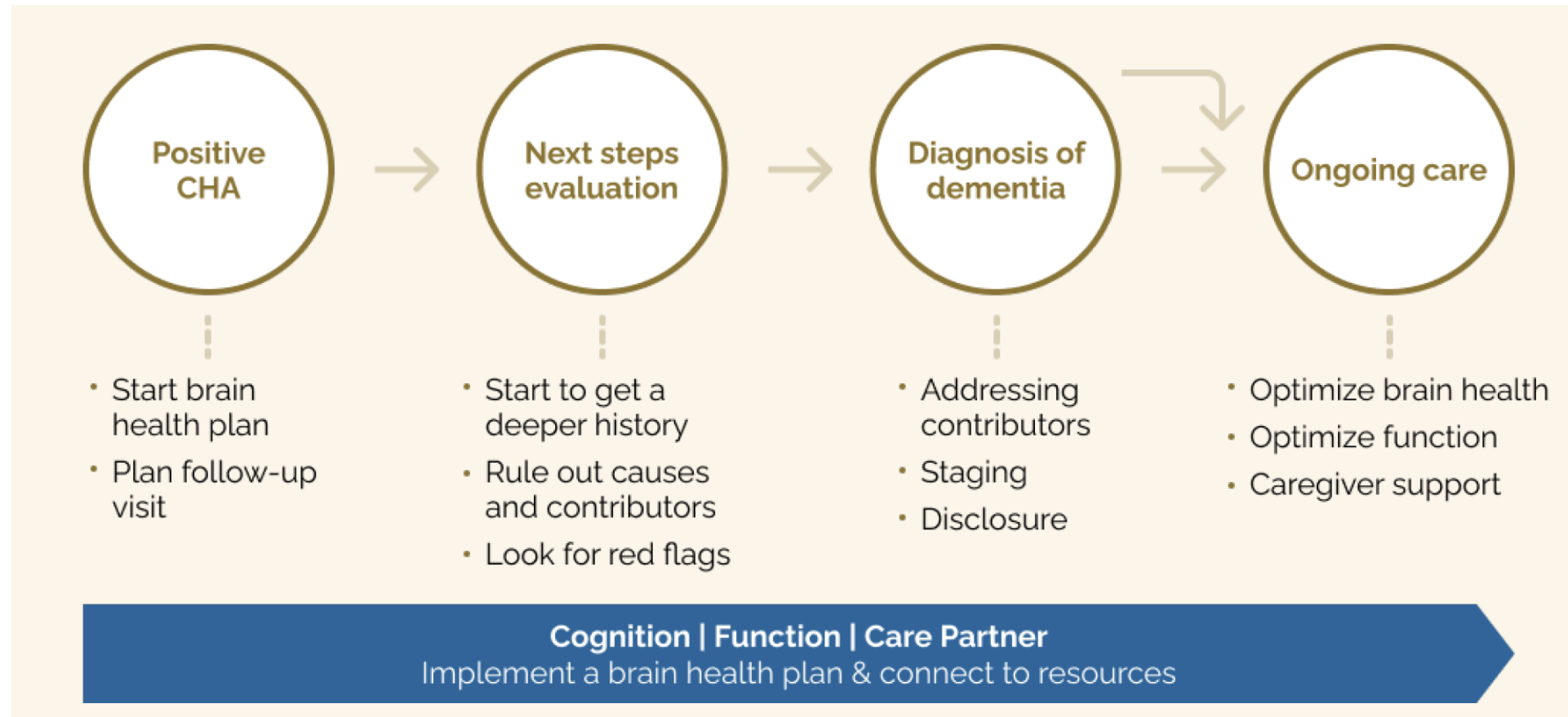
Screening for Dementia: The CHA

Goal: Screen Patients Over Age 65 Annually (Who Don't Have a Pre-existing Diagnosis of Dementia)



Allows you to start a brain health plan at the earliest detection of symptoms.

Screening to Diagnosis



Learning Objectives

1. State the purpose of using the Neuropsychiatric Inventory Questionnaire (NPI-Q) in patients with dementia
2. Identify 5 Common Behavioral and Psychological Symptoms of Dementia (BPSD)
3. Draft an initial plan of care to address BPSD

Natural History and Complications of Dementia

- Progression of cognitive decline
 - 3-4 points on MMSE/year
- Non-cognitive symptoms
 - Psychotic symptoms (20%)
 - Depressive symptoms (40%)
 - Agitation or aggression (80%)



Key Concepts in Managing BPSD

- To treat or not to treat...that is a good question
- Assessment: Need to ask the right questions and clarify caregiver understanding
 - NPI-Q (next slide)
- Behavioral Modifications (Part 2, October 24, 2023)
 - Implement before considering psychotropic medications
 - Should be continued even if management includes pharmaceuticals

Neuropsychiatric Inventory Questionnaire (NPI-Q)

Neuropsychiatric Inventory Questionnaire (NPI-Q)

- Validated tool based on the caregiver's report, based on past month
- Measures the presence, severity, and distress levels on 12 domains
- 5 minutes to complete *
- Always discuss caregiver's answers. This will help determine your care plan.
- Copyright-protected by Dr. Jeffrey L. Cummings if utilization is for-profit

<https://www.alz.org/media/documents/npq-questionnaire.pdf>

NPI-Q: Symptoms Reviewed

Delusions

Hallucinations

Agitation or
Aggression

Depression

Anxiety

Apathy

Elation

Irritability

Disinhibition

Motor
Disturbances

Sleep
Disturbances

Appetite
Changes

ADC Program | adcprogram.org

Neuropsychiatric Inventory Questionnaire (NPI-Q)

PAGE 1		NPI-Q	INTAKE
Patient Name: _____ Completed by: _____ Date: _____		Office Use Only	
Please answer the following questions based on changes that have occurred since the patient first began to experience memory problems. Mark "Yes" only if the symptom(s) has been present in the last <u>month</u> . For each item marked "Yes", please mark:			
SEVERITY of the symptom (how it affects the patient): 1 = Mild (noticeable, but not a significant change) 2 = Moderate (significant, but not a dramatic change) 3 = Severe (very marked or prominent, a dramatic change)	DISTRESS you experience due to that symptom (how it affects you): 0 = Not distressing at all 1 = Minimal (slightly distressing, not a problem to cope with) 2 = Mild (not very distressing, generally easy to cope with) 3 = Moderate (fairly distressing, not always easy to cope with) 4 = Severe (very distressing, difficult to cope with) 5 = Extreme or very severe (extremely distressing, unable to cope)		
Please answer each question carefully. Ask for assistance if you have any questions.			
Delusions Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Hallucinations Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Agitation/Aggression Is the patient resistive to help from others at times, or hard to handle? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Depression/Dysphoria Does the patient seem sad or say that he /she is depressed? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Anxiety Does the patient become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	

PAGE 2		INTAKE
Elation/Euphoria Does the patient appear to feel too good or act excessively happy? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Apathy/Indifference Does the patient seem less interested in his/her usual activities or in the activities and plans of others? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Disinhibition Does the patient seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Irritability/Lability Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Motor Disturbance Does the patient engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Nighttime Behaviors Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Appetite/Eating Has the patient lost or gained weight, or had a change in the type of food he/she likes? Comments: _____		<input type="checkbox"/> YES <input type="checkbox"/> NO (go to next question) SEVERITY DISTRESS 1 2 3 0 1 2 3 4 5 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Developed by Daniel Kaufer, MD. Final Version 6/99. © J.L. Cummings, 1994; all rights reserved		

NPI-Q

Delusions

Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?

Yes

No

SEVERITY: 1 2 3

DISTRESS: 0 1 2 3 4 5

Identifying Behavioral and Psychological Symptoms of Dementia (BPSD)

Delusions

False Beliefs

- People/family stealing from them
 - Spouse/partner is having an affair
 - Neighbors are conspiring against them
 - Delusions of grandeur
 - Capgras Syndrome (delusion that certain people are impostors)
- * Symptoms are very real to the patient



Hallucinations



False Visions or voices

- Angels
- Demons
- Bugs or snakes
- Small children
- Intruders in their home

Treatment strongly depends on severity and distress

Aggression

- #1 reason for placement in a facility
- Resisting help
- Threats toward caregivers
- Verbal and/or physical
- Mild: "Leave me alone. Stop telling me what to do."
- Severe: Physical aggression, such as hitting, kicking, pushing, etc.
- Assess patient's ability to inflict physical harm



Depression



Irritability

- Tearfulness, wishing they were dead
- Sadness
- Pessimism
- Isolating themselves from loved ones
- Dementia and depression often coincide. Untreated depression is associated with faster cognitive decline.

Anxiety

- Feelings of nervousness for no apparent reason
- Sundowning
- Wandering
- Pacing or unable to sit still
- Often stems from boredom and/or unspent energy



Apathy/Indifference



- Lack of interest in usual activities or previous interests
- Can be very distressing to families
- Examples
 - “wants to stay in bed all day”
 - “doesn't want to do anything”
 - “doesn't appreciate anything I do”

Elation/Euphoria

- Rare
- Feeling too good or excessively happy for no reason
- Seems “high on something”
- Examples
 - Singing
 - Dancing
 - Laughing (even if family has bad news)



Disinhibited Behaviors

- Behaviors that are inappropriate
- Hurtful comments or cursing
- Overtly friendly behavior (can be toward children)
- “No filter”
- Inappropriate comments to family or strangers
- Can be problematic in public (going outside naked or public urination)
- Sexual disinhibition



Sexually Disinhibited Behaviors

Person Living With Dementia (PLWD) may present

- Disrobing in public
- Exposing genital areas
- Delusions of spousal infidelity
- Overt or offensive sexual behaviors (public masturbation)
- Intimidating sexual behavior
- Pursuing pornographic material (magazines or videos)



Sexually Disinhibited Behaviors (continued)

Presentation

- Inappropriate sexual advances to a spouse, family members, friends, or caregivers (adult children)
- Inappropriate sexual comments
 - Excessive flirting
 - Storytelling of previous sexual encounters

Irritability



- Impatient with delays
 - Medical appointments
- Cranky
- Short-tempered

Motor Disturbances

- Falls
- Unstable gait
- Pacing
- Dysphagia
- Neurotic excoriations



Sleep Disturbances

- Affects 25-50% of all PLWD, often gets worse when disease progresses
- What is Insomnia?
 - Difficulty falling asleep >30 mins
 - Problems maintaining sleep (frequent awakenings)
 - Difficulty going back to sleep
 - Early morning awakenings
 - Daytime-nighttime reversal
 - *Donepezil side effect: Nightmares or vivid dreams

Causes of Sleep Disturbances Not Related to Dementia

Daytime napping

Lack of physical exercise

Immobility or prolonged periods in bed

Lack of daytime activities

Caffeine intake
(coffee, tea, soda)

Alcohol intake

Irregular sleep schedule

- Going out of town
- On vacation
- Plane rides

Poor sleep hygiene

Appetite Changes

- Weight Loss
- Weight Gain
- Preferences for sweets/carbs
- “My loved one only wants to eat _____ all the time”



The Initial Care Plan

- Support the caregiver
- Safety 1st (patient and caregiver)
 - Assess the patient's ability to inflict harm on themselves or the caregiver
 - Discuss the importance of help in immediate situations (911)
 - Psychiatric hospitalizations (5150)





The Initial Care Plan (continued)

- Caregiver Assessment
 - Level of education
 - Preferred way of learning
 - Health literacy
 - Social drivers of health
- Caregiver education
- Identify triggers
- Appropriate social activities
- Daily physical activity



Behavioral Symptoms in Dementia, Part 2: Management With Behavioral Modifications

October 24, 2023

Caregiver Videos

<https://www.uclahealth.org/medical-services/geriatrics/dementia/caregiver-education/caregiver-training-videos>

English



Spanish



UCLA Key Offerings through DCA

- Education on dementia for clinicians and health care teams
- Resources differ on intensity and commitment (driven by the learner's needs and objectives)

Dementia Mini-Course

An evidence-based, practical, and functional approach to the comprehensive care of older adults:

Process of participation:

Recorded videos can be viewed on the DCA website

Time commitment :
1 hour to 7 hours

Target Audience:

- geriatricians
- internists
- PCP and family medicine clinicians
- hospitalists and intensivists
- pharmacists
- other interested healthcare providers

Fee:

Free of charge

CME Credits available:

1 CME credit for 1 hour

National Dementia Care Collaborative (NDCC)

National community of health systems and others such as developers of complementary models, health policymakers, and government staff interested in spreading the ADC and improving the care of persons with dementia and their caregivers.

Process of participation:

Connect with the NDCC team

ADCProgramNLC@edc.org

Time commitment:

ongoing participation

Target Audience:

- Sites that have implemented the ADC
- Sites interested in implementing the ADC

Fee:

Free of charge

CME Credits available:

N/A

- Provides ongoing peer-to-peer feedback and group learning
- Work with the Dissemination Center and collaborating entities (Alzheimer's Association, American Geriatrics Society, AARP, Age-Friendly Initiative, LEAD Coalition, GAPNA) to distribute educational materials

ADC ECHO Series

Connects dementia care experts with health care teams from community-based settings in a free continuing education series of interactive, case-based video conferencing sessions.

Process of participation:

Sign up for free by emailing the Alzheimer's Association

rbgoldberger@alz.org

Time commitment :

an ECHO series lasts six months with a biweekly meeting. Each ECHO topic is 1 hour long

Target Audience:

Health care providers who would like to better understand Alzheimer's and other forms of dementia and emphasize high-quality, person-centered care

Fee:

Free of charge

CME Credits available:

1 CME credit for 1 hour

ADC Dissemination

ADC partners with community-based organizations (CBOs) to provide comprehensive, coordinated, person-centered care for patients with Alzheimer's and other dementias. The program aims to maximize patient function, independence, and dignity, minimize caregiver's strain and burnout, and reduce costs through improved care.

Process of participation:

Fill out an interest form
<https://www.adcprogram.org/interest-form>
to schedule a call with the team

Time commitment :

UCLA will provide support for two years to implement

Target Audience:

- Academic and Non-academic health centers
 - Health Plans
 - CBO
- Medical groups
 - VA facilities
 - CCRCs
 - PACE

Fee:

Through DCA, the \$50,000 fee is waived.

CME Credits available:

N/A

Guiding an Improved Dementia Experience (GUIDE) Model

On July 31, 2023, the Centers for Medicare & Medicaid Services (CMS) announced a new voluntary nationwide model – the Guiding an Improved Dementia Experience (GUIDE) Model that aims to:

- Improve the quality of life for people living with dementia
- Reduce burden and strain on unpaid caregivers of people living with dementia
- Prevent or delay long-term nursing home care.

<https://innovation.cms.gov/innovation-models/guide>

Referrals to other Dementia Care Models

- Care Ecosystem
- The Benjamin Rose Institute Care Consultation Program (BRI CC)
- Maximizing Independence (MIND-at-Home)
- The Eskenazi Healthy Brain Institute (HABC)
- The Integrated Memory Care (IMC): Emory

Thank you!

Michelle Panlilio, DNP, GNP-BC
National Lead Dementia Care Specialist
UCLA Alzheimer's and Dementia Care Program





Have more questions? Get answers through our
Warmline @ **1-800-933-1789** or our support page.

Here are some examples.

What do
I prioritize after a
positive CHA?

Is the CHA
covered for
patients over
age 65 who have
Medicare, but not
Medi-Cal?

Can I use the CHA
for a patient with
limited literacy?



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



Or visit: www.dementiacareaware.org

Dementia Care Aware on Social Media



Follow us and get updates delivered to your favorite social media channel:

- LinkedIn
- Facebook
- YouTube

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 CE, including 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 your first name, last name, profession, and claim **1 CE credit** for the webinar.