Alzheimer's Disease and Related Disorders Advisory Committee Meeting

CalHHS
California Health & Human Services Agency

Meeting Logistics

- **Join by smart phone, tablet, or computer**:
  https://us06web.zoom.us/j/84260169272
- **To join by phone (audio only):**
  Tel: 888-788-0099 | Meeting ID: 846 6016 9272
- **Live captioning** accessible via webinar (Zoom)
- **American Sign Language Interpretation** via webinar (Zoom)
- **Recording, Slides, and Transcripts** will be posted to the CalHHS Alzheimer's Disease & Related Disorders webpage post webinar

Public Comment

Time is reserved on the meeting agenda for public comment.

- **In-Person Comments:** Raise your hand to enter the line to make a public comment or ask a question.
- **Verbal Comments:** You can "raise your hand" in the Reactions feature of Zoom or press *9 on your phone dial pad to enter the line for a verbal comment or question. The moderator will unmute your line.
- **Written Comments:** You may submit comments and questions throughout the meeting using the **Zoom Q&A.**

Welcome and Introductions

Darrick Lam

Committee Vice Chair

Family Member Representative

Vice President, Self-Help for the Elderly

Today's Agenda

I. Welcome & Introductions
II. Recognizing Californians Living with Dementia and Their Caregivers
III. Supporting Unpaid Caregivers of People Living with Dementia (with discussion)
IV. Lunch Break
V. Older Americans Act/Older Californians Act Modernization
VI. BOLD Public Health Programs Grant
VII. Priorities from August Presentation
VIII. Legislative Update (with Discussion)
IX. Finalization of Recommendations & Items for CalHHS Secretary
X. Public Comment
XI. Closing Comments & Next Steps

Committee Member Introductions

California Department of AGING

Committee Chairs

- **Catherine Blakemore**, *Family Member Representative* (Chair)
- **Darrick Lam**, *Family Member Rep* (Vice Chair)

Stakeholder Committee Members

- **Andrea Robert**, *Consumer Rep*
- **Barbra McLendon**, *Alzheimer's Los Angeles, Service Provider Rep*
- **Celine Regalia**, Providence Community Health Napa Valley, *Alzheimer's Day Care Resource Center Rep*
- **Dr. Dolores Gallagher Thompson**, *Stanford University, Social Research Rep*
- **Julie Souliere**, *CA Health & Human Services Agency*

Committee Member Introductions

Stakeholder Committee Members (Cont.)

- **Meg Barron**, *Alzheimer's Association, Consumer Organization Rep*
- **Sally Bergman,** *Elder Law Rep*
- **Dr. Sarah Tomaszewski Farias**, *UC-Davis, Alzheimer's Disease Diagnostic & Treatment Centers Rep*
- **Todd Shetter**, *ActivCare Living, Service Provider Rep*
- **Dr. William Mobley**, UC San Diego, *Academic Medical Research Rep*
- **Dr. Wynnelena Canlas Canio**, *Kaiser Permanente, Mental Health Field Rep*
- **Vacant**, *Consumer Rep*

Recognizing Californians Living with Dementia & Their Caregivers

Mark Ghaly, MD, MPH

Secretary
California Health and Human Services Agency (CalHHS)

Supporting Unpaid Caregivers of People Living with Dementia

Behavioral Risk Factor Surveillance System (BRFSS) 2021 – Caregiver Module California Results – Dementia Caregivers

Alzheimer's Disease Program
Chronic Disease Control Branch
Center for Healthy Communities
California Department of Public Health

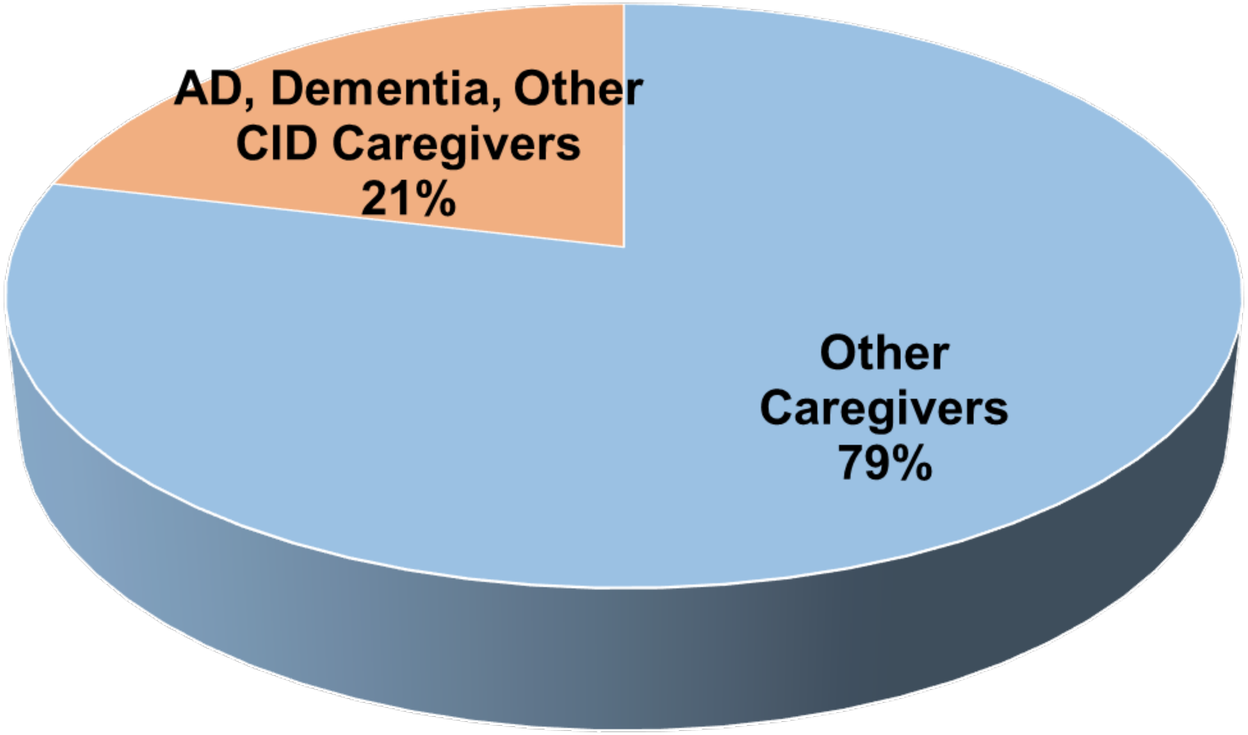
Prepared by: Angalar Chi, DHSc, MPH
Research Scientist II
Health Information & Statistics Section

CDPH
California Department of
PublicHealth

Methodology

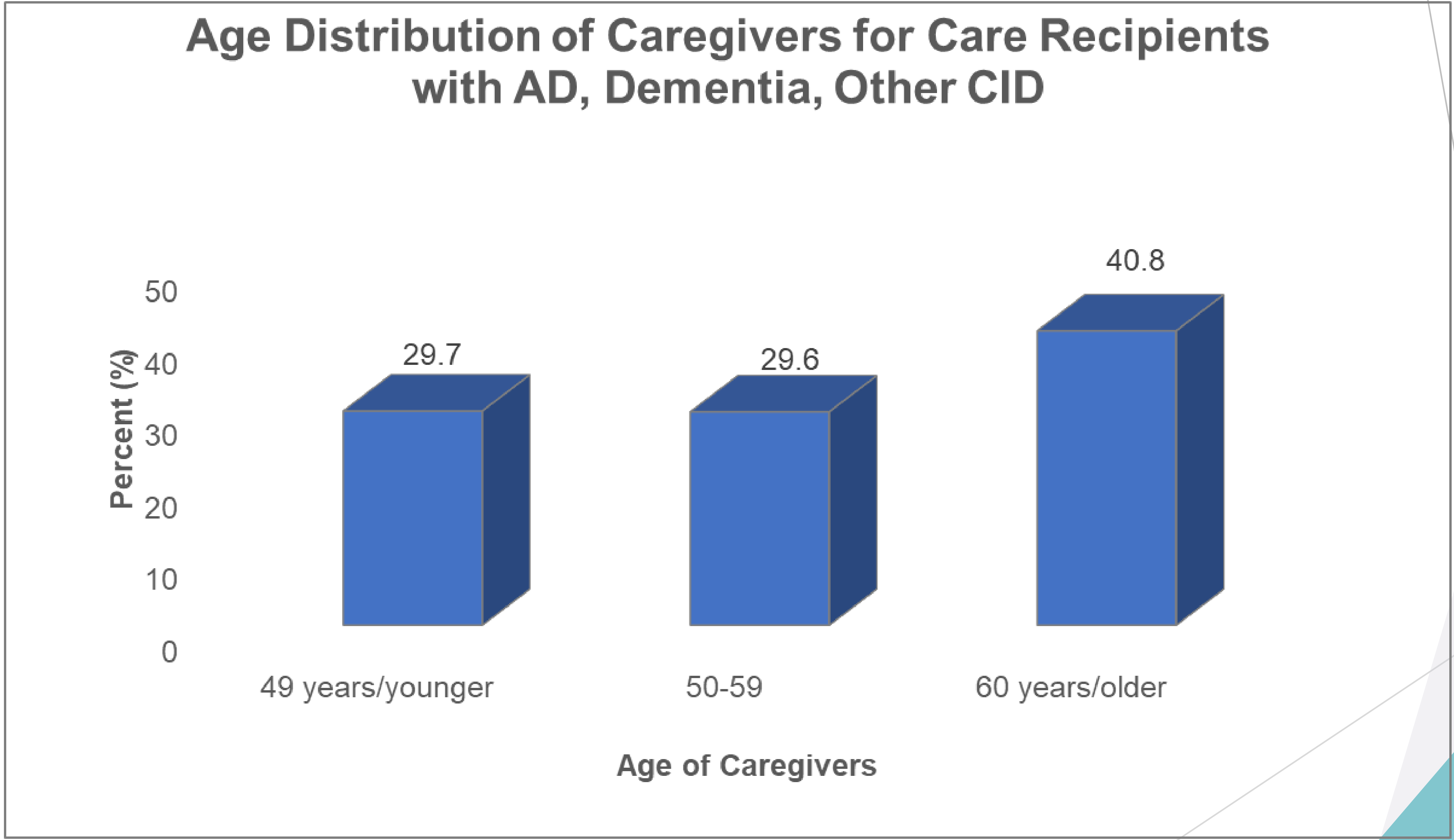
- **Questionnaire Design**
  1. Core Questions
  2. Modules
     - **BRFSS 2021 – Caregiver Module**
     - BRFSS 2020 – Cognitive Decline Module
- **Eligibility Criteria**
  - California residents ages 18 years and older
  - Live in households or college housing
- **Sampling – Randomly selected from 2 sampling frames**
  - Landline: Randomly selected one person per household
  - Cell Phone: Person who answered the phone and primary user
- **California data**
  - 2,496 total, of which 528 were caregivers
  - Caregiver: reported having provided regular care or assistance to a friend or family member who has a health problem or disability in the last 30 days

Percentage of Caregivers Providing Care to Recipients with Alzheimer's Disease, Dementia, or Other Cognitive Impairment



CDPH
California Department of PublicHealth

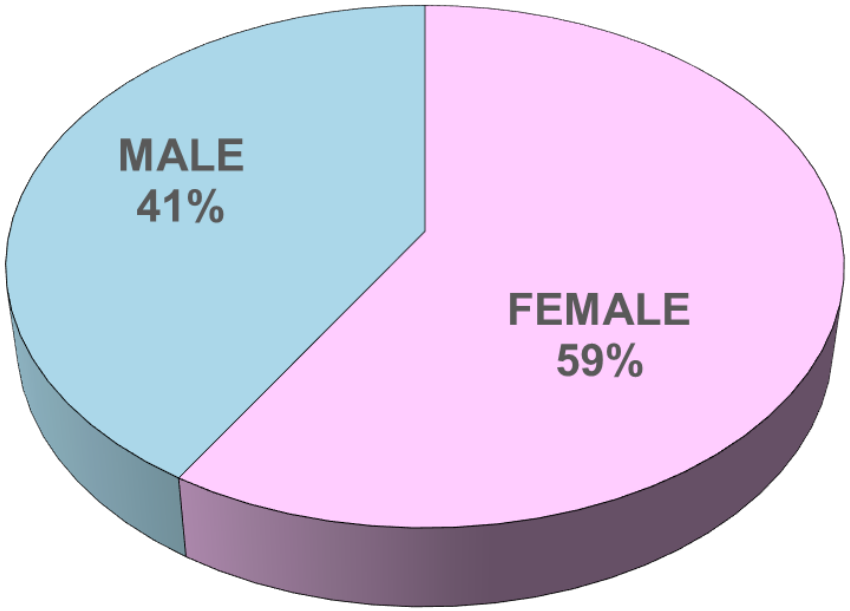
CA Caregiver Demographics: Age



California Department of PublicHealth

CA Caregiver Demographics: Sex

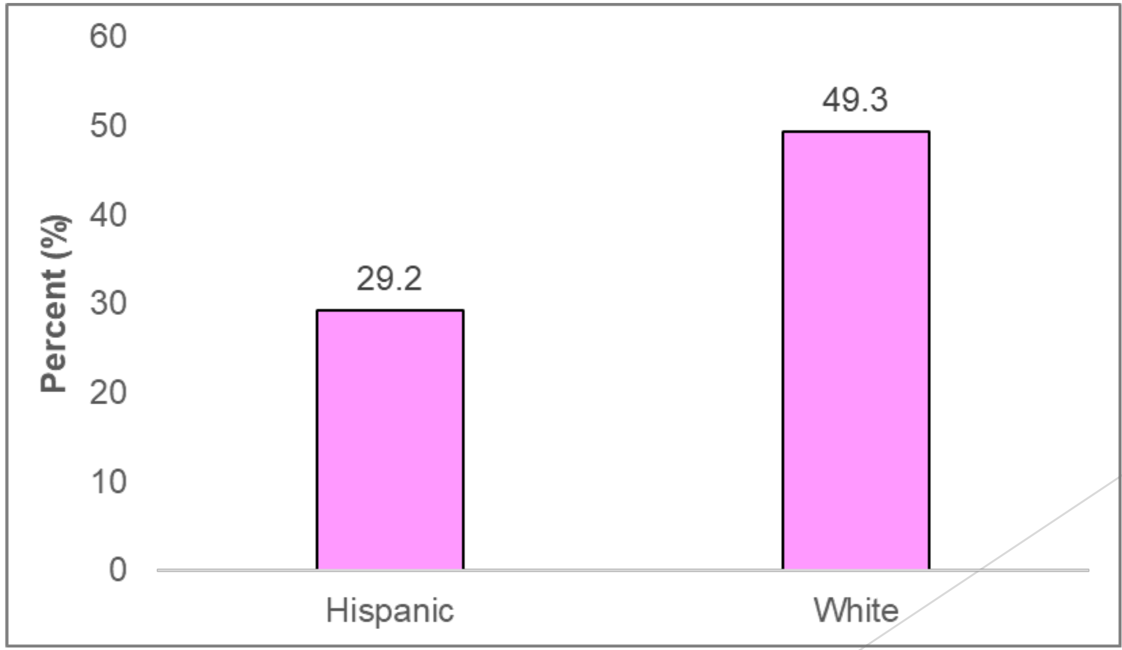
- Caregivers who provided care to a family member or friend with AD, Dementia, or other cognitive impairment disorder



CA Caregiver Demographics: Race/Ethnicity

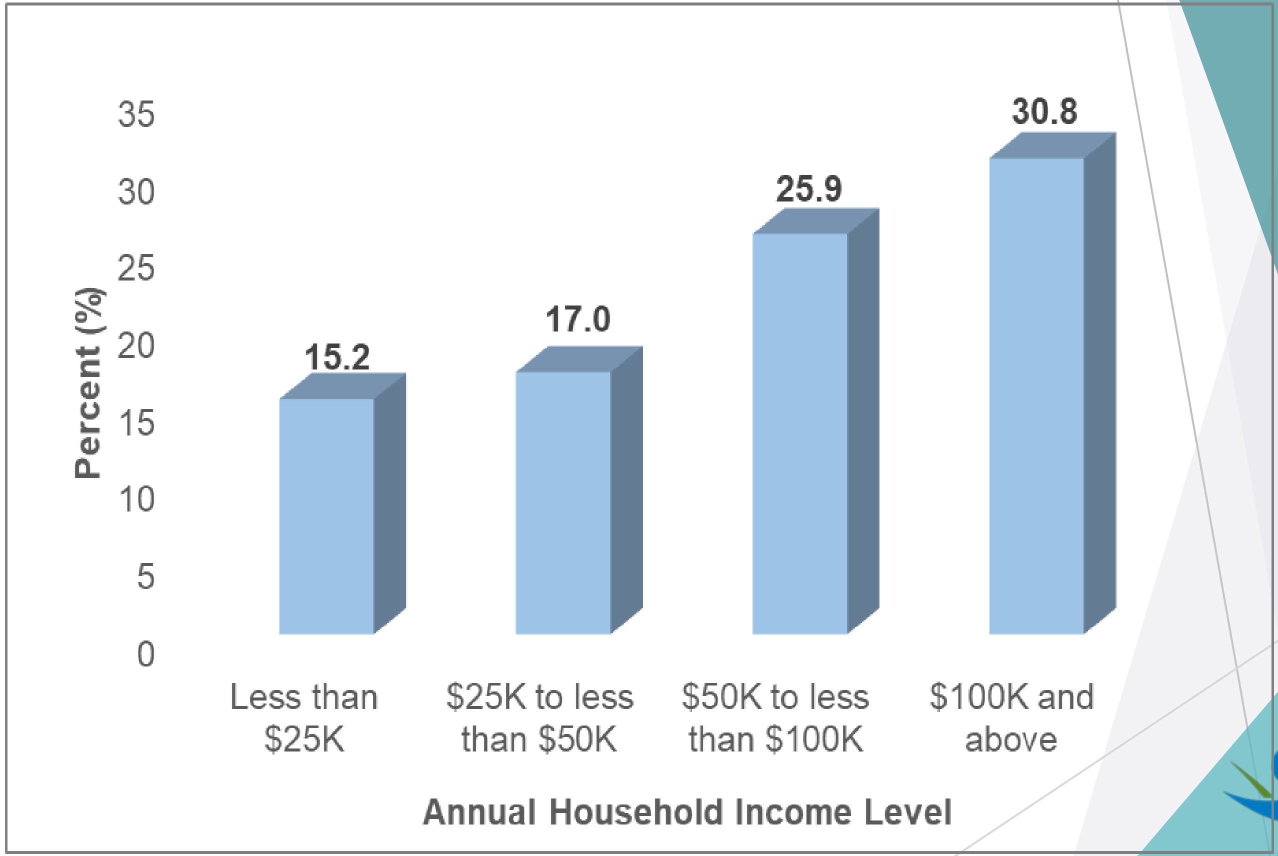
- Caregivers who provided care to a family member or friend with AD, Dementia, or other cognitive impairment disorder
- Asterisk (*) = Data suppression applied due to counts <15 or RSE >30%
- Data points do not add up to 100% in the graph due to the exclusion of groups resulted from suppression

Race/Ethnicity
White
Black/African American*
American Indian/Alaska Native*
Asian*
Multiracial, non-Hispanic*
Hispanic

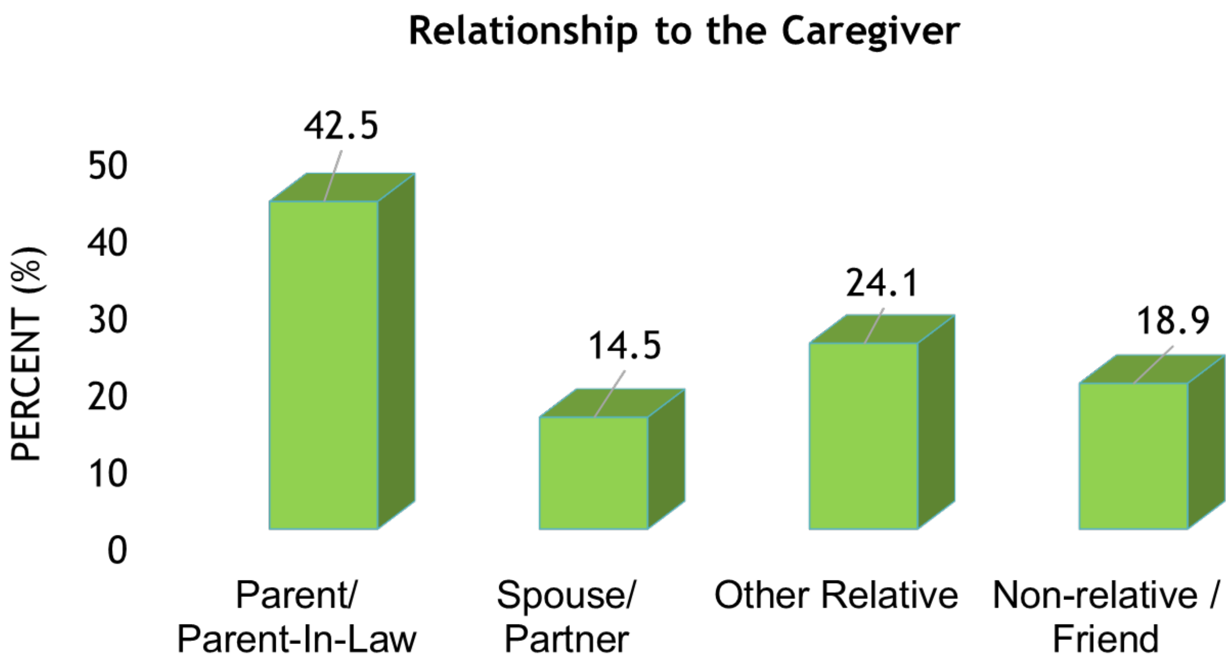


Caregiver’s Household Income

- Caregivers who provided care to a family member or friend with AD, Dementia, or other cognitive impairment disorder
- Unknown income is not included in this chart
- Data points do not add up to 100% in the graph due to the exclusion of the “Unknown” category



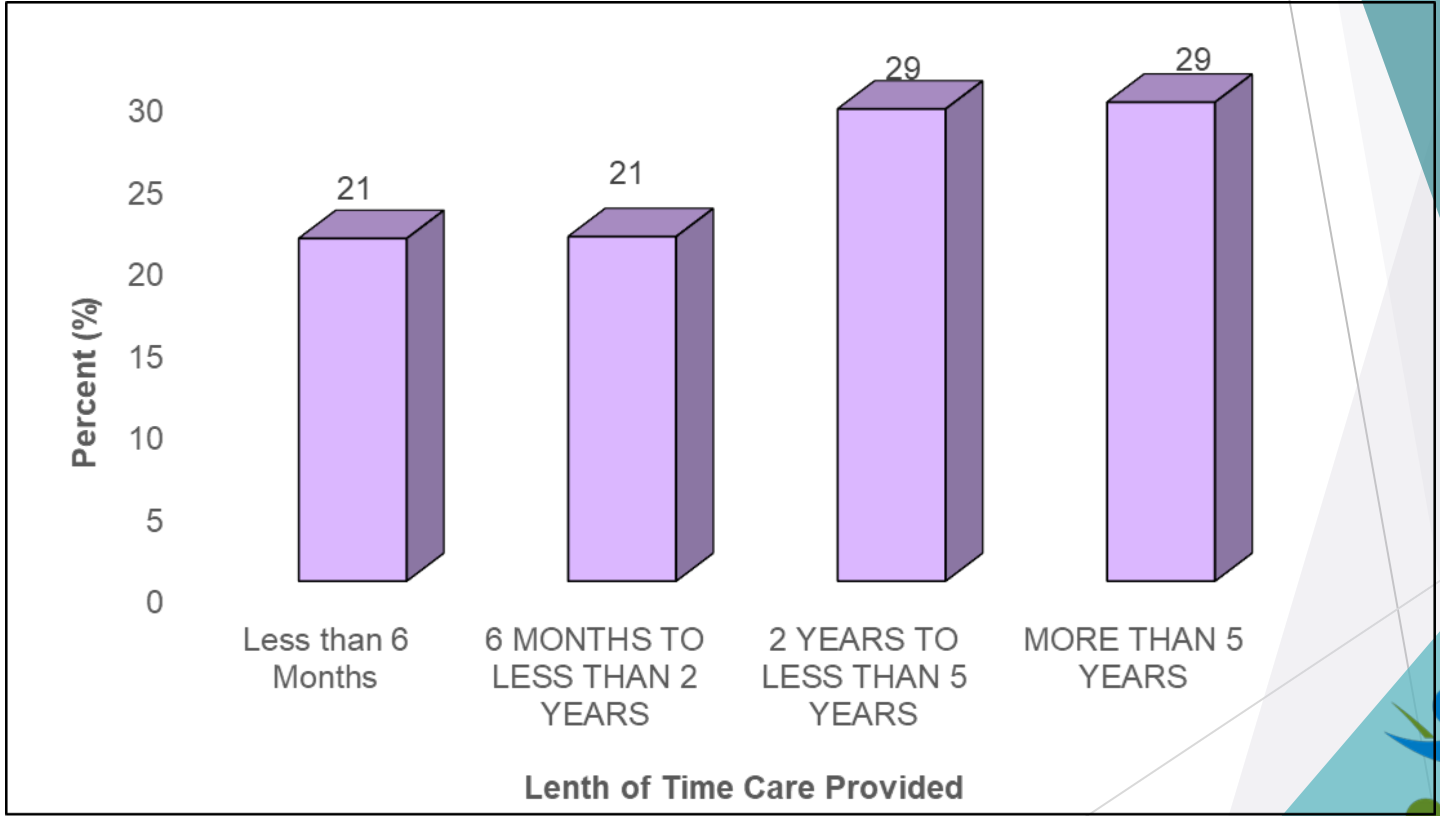
Care Recipient's Relationship to Caregiver



- 20.2 CAREREALB: What is his or her relationship to you (care recipient with AD, dementia, or CID)?

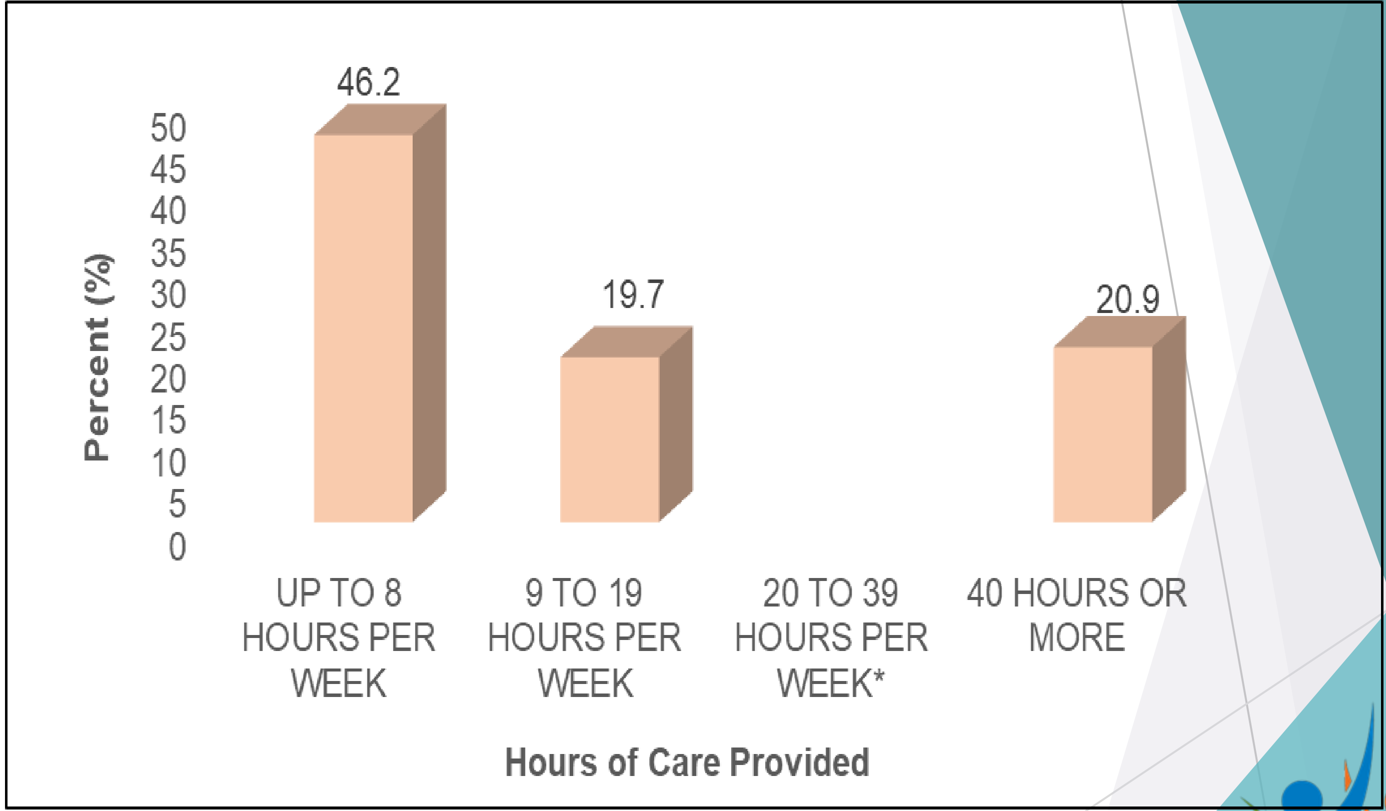
Length of Time Spent Providing Care

- 20.3 CARELONG: For how long have you provided care for that person (with AD, dementia, or other CID)?



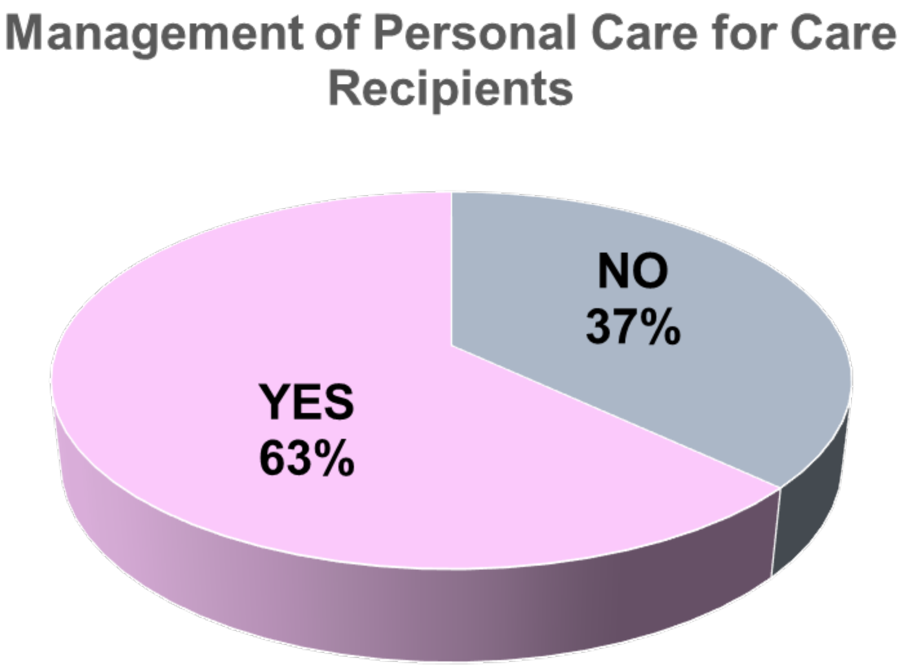
Hours of Care Provided

- 20.4 CAREHOUR1: In an average week, how many hours do you provide care or assistance (for persons with AD, dementia, or other CID)?
- Asterisk (*) = Data suppression applied due to counts <15 or RSE >30%
- Unknown hours of care is not included in this chart
- Data points do not add up to 100% in the graph due to the exclusion of the category: “Unknown” and data suppression



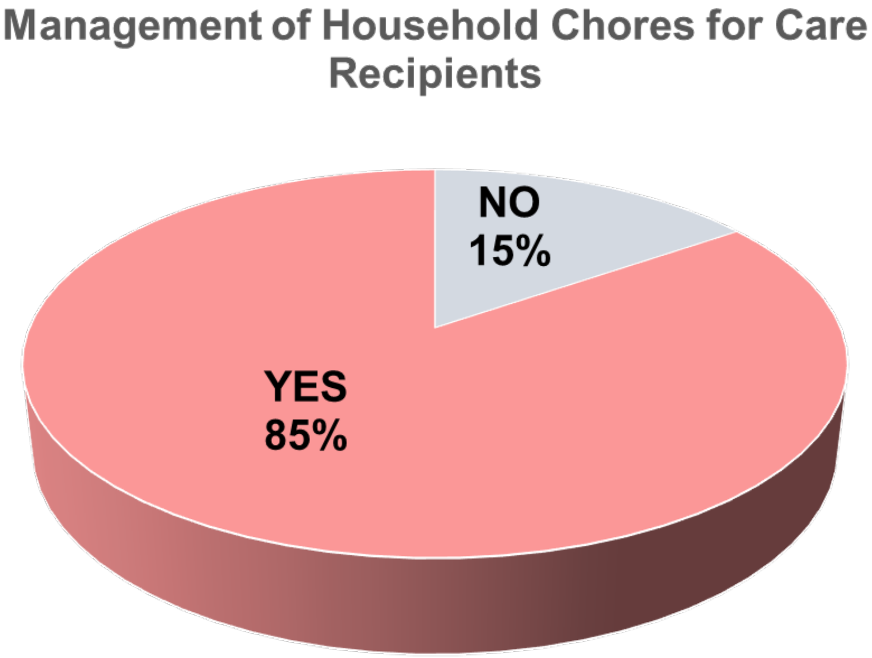
Managing Personal Care?

- 20.7 CRGVPERS: In the past 30 days, did you provide care for this person (with AD, dementia, or other CID) by managing personal care such as giving medications, feeding, dressing, or bathing?



Managing Household Chores?

- 20.8 CRGVHOUS: In the past 30 days, did you provide care for this person (with AD, dementia, or other CID) by managing household tasks such as cleaning, managing money, or preparing meals?



California Department of Public Health

Questions/Comments?

- If you have any comments about the presentation, please contact the Alzheimer’s Disease Program: AlzheimersD@cdph.ca.gov.
- More on BRFSS:
  - Centers for Disease Control and Prevention
  - CDPH Chronic Disease Surveillance & Research Branch

UC DAVIS HEALTH

CALIFORNIA caregiver Resource Centers
Educate. Connect. Support.

FCA Family Caregiver Alliance®

FAMILY CAREGIVING INSTITUTE

BETTY IRENE MOORE SCHOOL OF NURSING

Profile of Caregivers in California Caregiver Resource Centers:

Analysis of Data from CareNav™

Janice F. Bell, MN, MPH, PhD, FAAN
Professor/Associate Dean, Betty Irene Moore School of Nursing

Heather M. Young, PhD, RN, FAAN, FGSA
Professor, Betty Irene Moore School of Nursing

UCDAVIS
HEALTH

California Caregiver Resource Centers Evaluation Team

FAMILY CAREGIVING INSTITUTE

BETTY IRENE MOORE SCHOOL OF NURSING

Jennifer Mongoven, MPH, Co-Investigator
Associate Director for Operations, FCI

Robin Whitney, PhD, RN, Co-Investigator

Orly Tonkykh, PhD, RN, Post-Doctoral Fellow

Benjamin Link, BS

Jessica Famula, MPH

Data Source: CareNav^{TM}

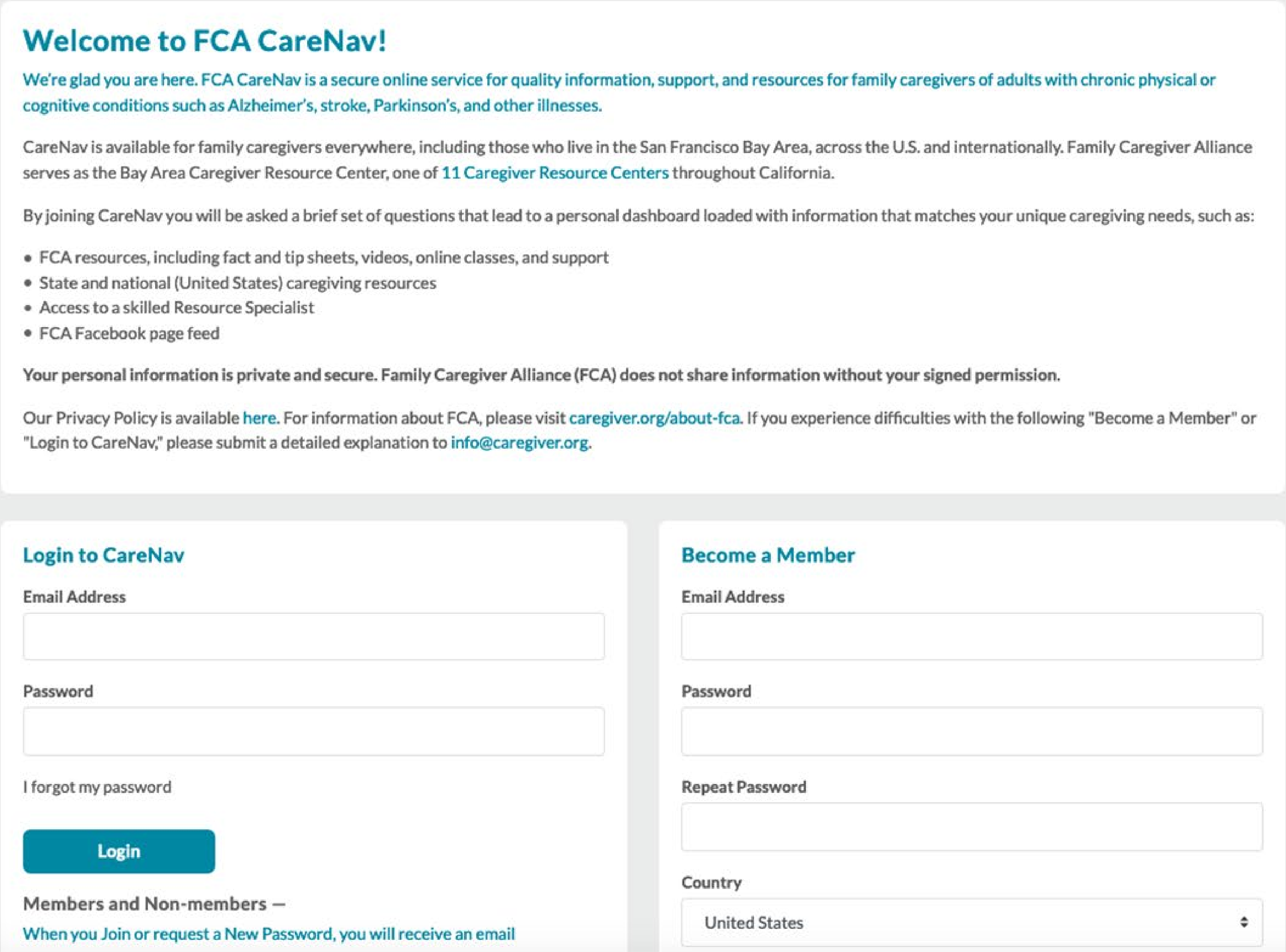
- Cloud-based, HIPAA compliant client record system

- Interactive family caregiver record

- Client dashboard with tailored information, agency contacts/information, care plan, secure communications (additional functions scheduled for 2021/22)

- Service use data (intake, assessment, other) exported for analysis

Welcome to FCA CareNav



Welcome to FCA CareNav!

We're glad you are here. FCA CareNav is a secure online service for quality information, support, and resources for family caregivers of adults with chronic physical or cognitive conditions such as Alzheimer's, stroke, Parkinson's, and other illnesses.

CareNav is available for family caregivers everywhere, including those who live in the San Francisco Bay Area, across the U.S. and internationally. Family Caregiver Alliance serves as the Bay Area Caregiver Resource Center, one of 11 Caregiver Resource Centers throughout California.

By joining CareNav you will be asked a brief set of questions that lead to a personal dashboard loaded with information that matches your unique caregiving needs, such as:

- FCA resources, including fact and tip sheets, videos, online classes, and support
- State and national (United States) caregiving resources
- Access to a skilled Resource Specialist
- FCA Facebook page feed

Your personal information is private and secure. Family Caregiver Alliance (FCA) does not share information without your signed permission.

Our Privacy Policy is available here. For information about FCA, please visit caregiver.org/about-fca. If you experience difficulties with the following "Become a Member" or "Login to CareNav," please submit a detailed explanation to info@caregiver.org.

Login to CareNav

Email Address

Password

I forgot my password

Members and Non-members —

When you Join or request a New Password, you will receive an email

Become a Member

Email Address

Password

Repeat Password

Country

United States

Family Caregiver Alliance®

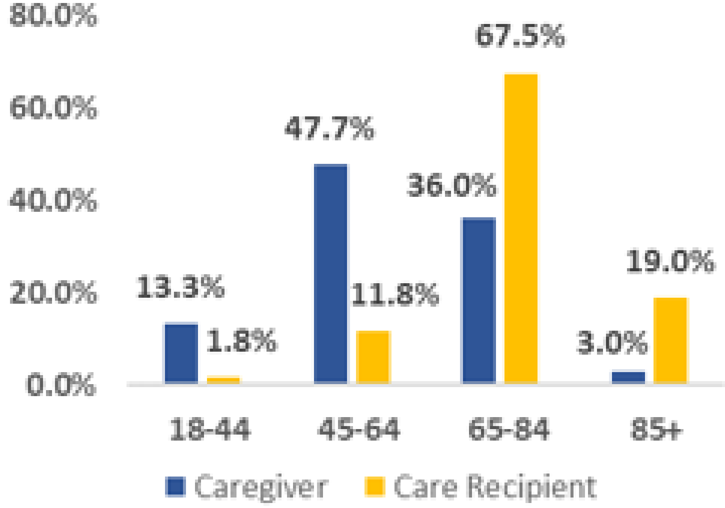
CareNav™ Provides an Online Assessment covering:

- Direct Care
  - ADLs/IADLs
  - Medical Tasks
  - Memory and Behavior Problems
  - Health Care Utilization
  - Technology Use
- Plan Care
  - Insurance
  - Legal Documents
  - Paid/Upaid Supports
- Self-Care
  - Caregiver Health
  - Burden Scale
  - PHQ9
  - Loneliness Scale

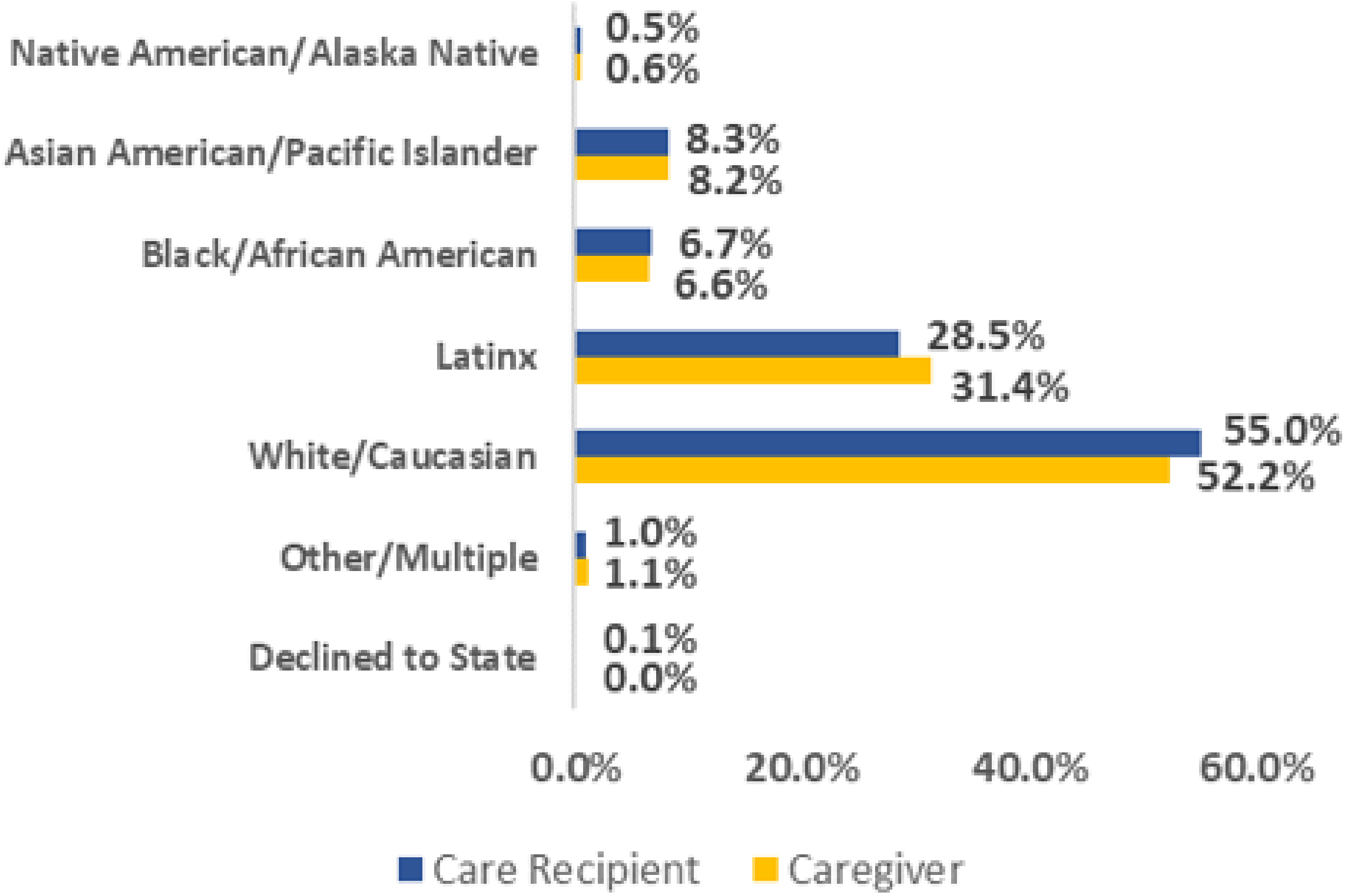
Who are the caregivers and care recipients?

Age

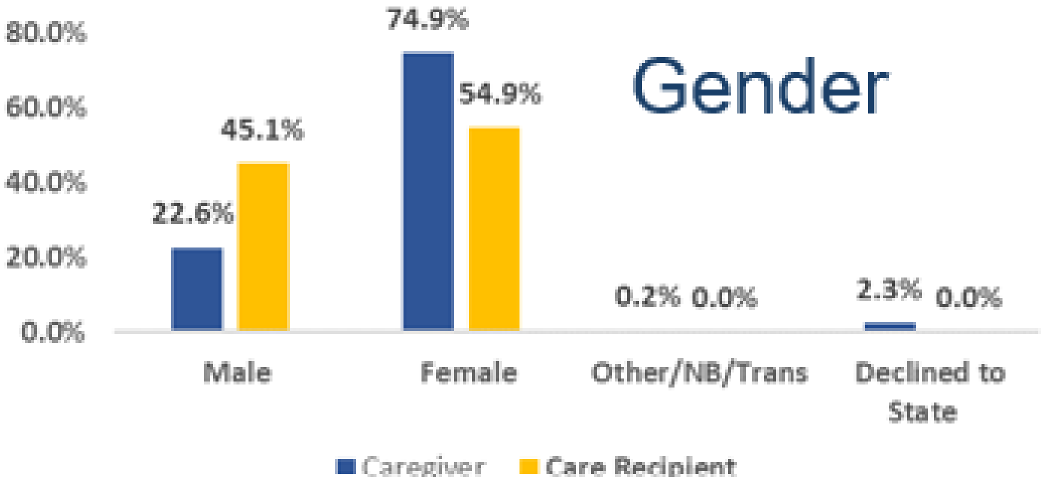
n = 4,299



Race/Ethnicity



Gender



Caregiver Characteristics

- ✓ 26% work FT; 11% PT
- ✓ 18% earn below FPL
- ✓ 65% married or partnered
- ✓ 90% identify as heterosexual
- ✓ 18% provide care to multiple care recipients
- ✓ 13% live in a rural area
- ✓ 5% have Veteran’s Administration benefits

Care Recipient Characteristics

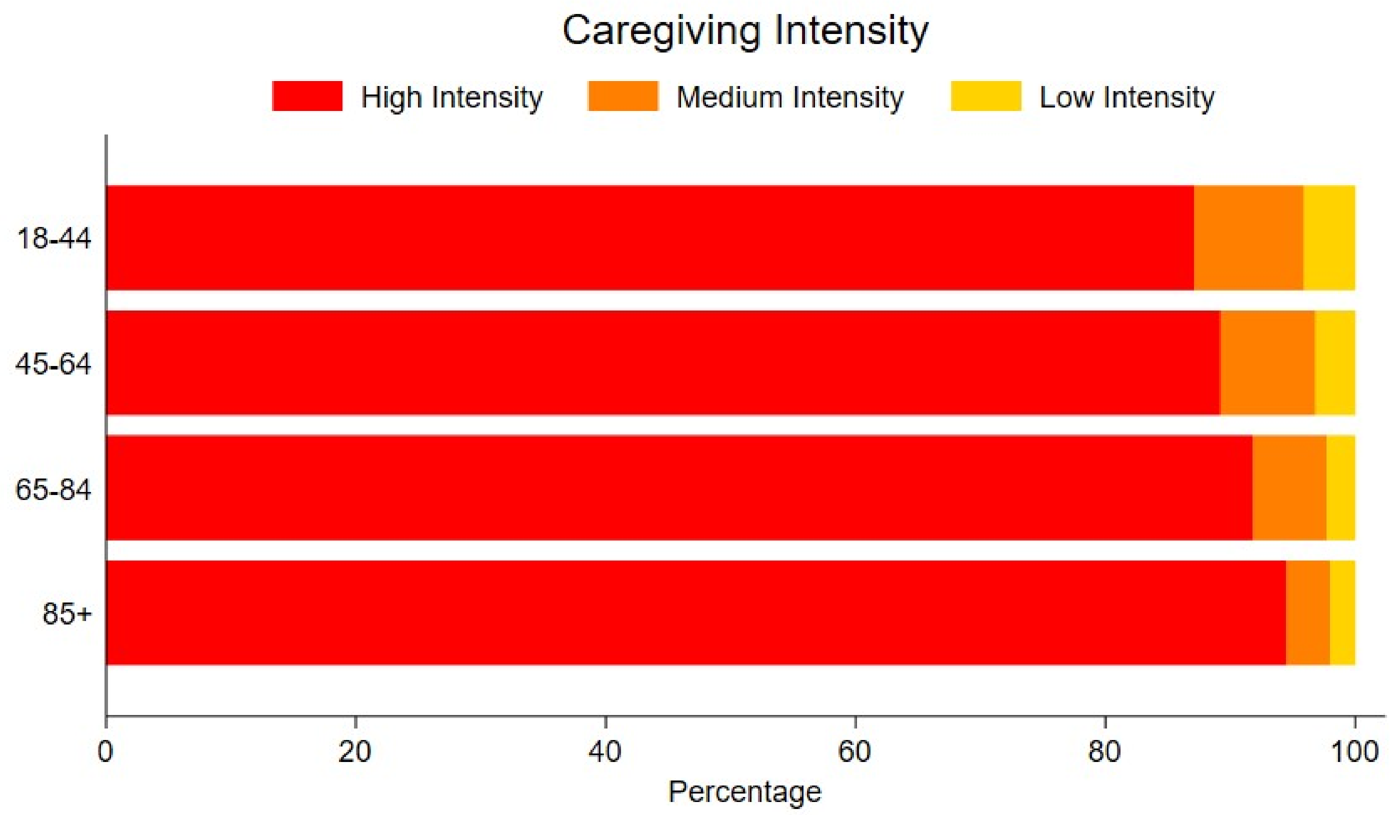
Relationship to Care Recipient	%
Spouse/partner	34.8
Child	51.7
Other relative	9.9
Friend	2.6

Special Needs	%
Memory Loss	91.3
Cannot be left alone	46.3
Wandering	15.7

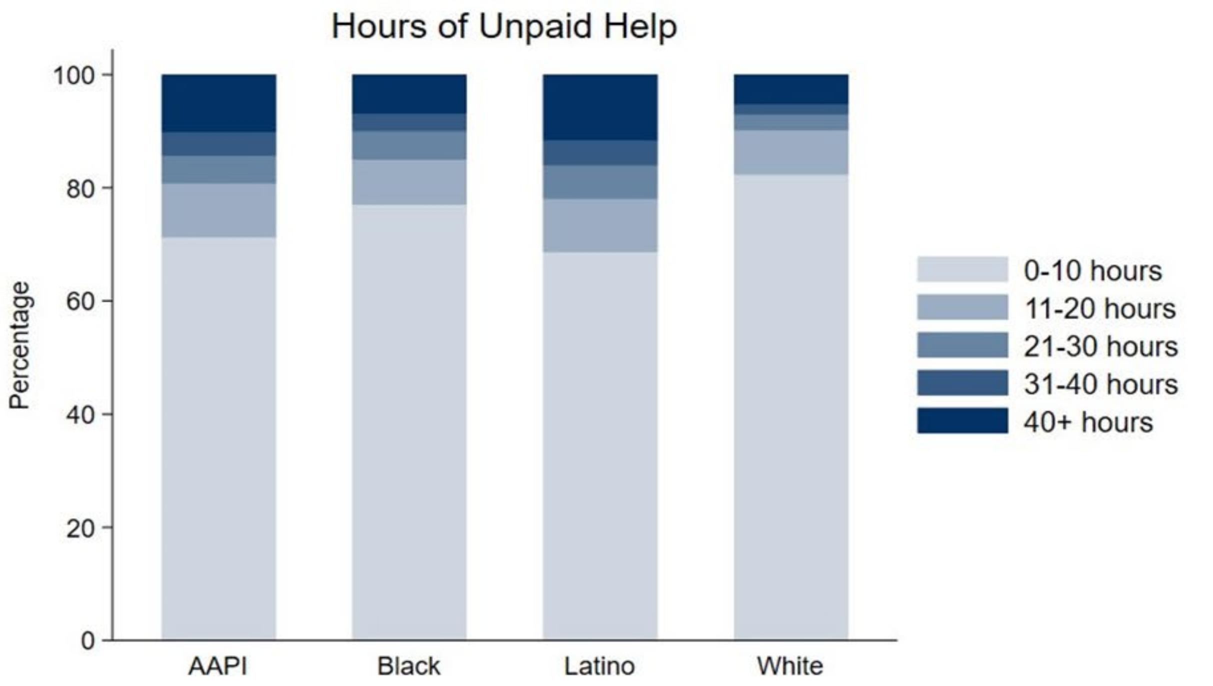
Primary Diagnosis	%
Alzheimer’s Disease or related dementias	68.3
Parkinson’s	7.3
Stroke	10.5
Cancer	3.5
Brain Injury	2.8
Other	7.6

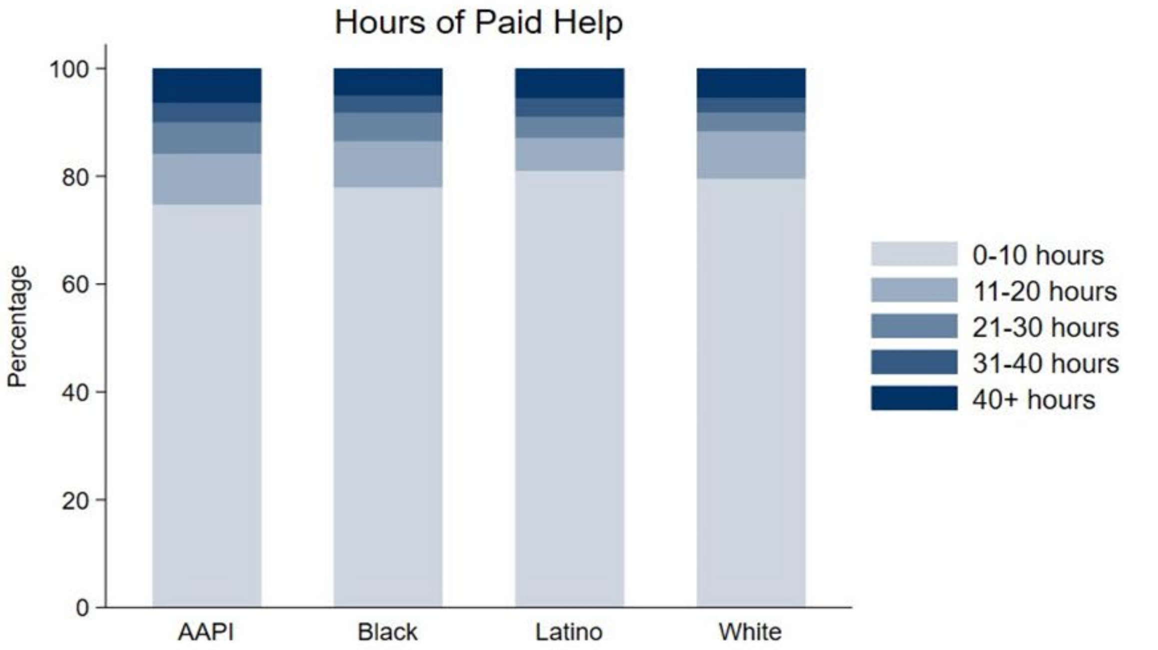
Caregiving Intensity

- ✓ Caregiving intensity increases with caregiver age
- ✓ More high intensity care among caregivers who identify as Asian American and Pacific Islander, Black non-Hispanic, Hispanic or Latino compared to White, non-Hispanic
- ✓ More high intensity care among caregivers living below the federal poverty level



Paid and Unpaid Help





- ✓ Most caregivers have no paid or unpaid help
- ✓ Percentages differ by race and ethnicity
- ✓ Less unpaid help with older age
- ✓ Less paid and unpaid help with lower income
- ✓ Less paid and unpaid help with rural (versus urban) residence

CRC Caregivers compared to State and National (%)

Dimension	CRC caregivers (n=4,299)	State (CHIS) (n = 2,995)	National (Caregiving in the US) (n = 1,627)
Age (years)			
18 – 44	13.3	17.5	34.3
45 – 64	47.7 ↑	44.1	38.5
65 or older	39.0	38.3	27.2
Gender (% female)	70.3 ↑	62.8	60.2
Race/ethnicity			
Native American/Alaska Native	0.6 ↑	0.73	
Asian American/Pacific Islander	8.2	9.55	4.8
Black non-Hispanic	6.6	3.9	13.6
Latinx	31.4	18.2	15.2
White non-Hispanic	52.2	64.6	63.6
Multi-racial/other	1.1	3.0	2.8
Employment (% working)	40.0 ↓	48.4	55.6
Relationship status (% married/partnered)	68.2 ↑	57.9	62.6

CRC Caregivers compared to State and National (%)

Dimension	CRC caregivers (n=4,299)	State (CHIS) (n = 2,995)	National (Caregiving in the US) (n = 1,627)
Hours/week caregiving (% over 40 hours)	72.9 ↑	9	32.0
Relationship to care recipient			
Spouse/Partner	34.8 ↑	19.5	16.8
Child	51.7	9.6	6.7
Other relative	9.9	54.5	64.8
Non-relative	2.6	13.0	11.7
Care recipient diagnosis (% ADRD)	68.3	5.1	5.7
Care intensity	(n=3,788)		
Low	2.8	-	43.5
Medium	6.8	-	15.5
High	90.4 ↑	-	41.0
Assists with medical/nursing tasks	78.6 ↑	-	57.7

CRC Caregivers compared to State and National (%)

Dimension	CRC caregivers (n=4,299)	State (CHIS) (n = 2,995)	National (Caregiving in the US) (n = 1,627)
Self-rated Health			
Excellent/Very Good/Good	68.8	85.4	80.0
Fair	24.6 ↑	11.9	17.2
Poor	6.7	2.8	2.8
Caregiving made health worse	34.5 ↑	-	21.8
UCLA Loneliness Scale (% lonely)	35.1 ↑	5.1	-

Discussion

- ✓ Most CRC caregivers provide care for individuals with memory loss, Alzheimer’s or related dementias
- ✓ CRC caregivers represent a “help-seeking” population engaged in complex and high intensity care in the home
- ✓ State and national surveys do not capture the intensity of care provided by this population of caregivers
- ✓ CareNav^{TM} data is an important adjunct to state and national surveys for caregiver interventions and policy

Questions?

Contact: jfbell@ucdavis.edu

A Family Caregiver's Experience

Hilda Gutierrez

California Department of AGING

California’s Support for Dementia Caregivers

Denise Likar, Deputy Director, California Department of Aging

What Services are Available?

- Education/ Information & Assistance
- Advanced Care Planning
- Engagement Activities
- Support Groups
- Task Assistance
- Direct Care (In home/In community)
- Respite
- Care Management

Challenges to Accessing Services

- Not available statewide
- Inconsistency community by community
- Eligibility criteria
- May be fee based
- Limited capacity
- Language barriers
- Lack of culturally appropriate services
- Navigation challenges

Working towards the Future

Statewide Initiatives

- California Department of Public Health Caregiver Training
- Older Adult Behavioral Health Initiative
- Caregiver Resource Centers
- Statewide Older Adult Survey
- No Wrong Door

Master Plan for Aging Initiatives

- Workforce and training
- Community Health Workers
- Caregiver equity roadmap
- Home and Community Based Services gap analysis
- Caregiver training and education resources
- Equity metrics
- Dementia Care Aware
- Cal-COMPASS

Providence

California Community Program for Alzheimer's Services and Supports (Cal-COMPASS) & Its Future

Celine Regalia, MSW, MA
CCC-SLP

Adult Day Services & Alzheimer's Day Care Resource Center Designation

Adult Day Services

Adult Day Services programs offer a safe, positive, caring alternative to nursing home care for those who do not need 24-hour skilled nursing. These programs are designed to help people stay mentally and physically active, reduce isolation improve their health, and prevent the decline of their abilities.

Alzheimer's Day Care Resource Center Designation

Alzheimer’s Day Care Resource Centers (ADCRC) designation was granted to licensed ADP’s or ADHC/ CBAS centers offering specialized Alzheimer’s care for moderate to late-stage Alzheimer’s patients or persons with similar conditions. A highly trained team applies a philosophy of care emphasizing dignity and respect while fostering optimal independence according to each patient’s level of functioning. Also provided are caregiver respite and caregiver support.

Source: California Association for Adult Day Services

Providence Adult Day Health Napa Valley
Alzheimer’s Day Care Resource Center

Our Alzheimer’s Resource Center Provides:

- Accessibility and availability of quality dementia care for those diagnosed with Alzheimer’s disease or other forms of dementia.
- Assistance for dementia patients to function at the highest possible level through therapeutic activities.
- Support for caregivers through counseling, family consultations, caregiver support groups, education, training and respite,
- Training opportunities for students, professionals, and caregivers
- Community resources, including a lending library, educational opportunities and information and referral

Free Family Consultations:

- No cost family consultations for those who have a diagnosis of Alzheimer’s or other forms of dementia, their families and caregivers.
- Consultations are led by a medical social worker.
- Available on site, in the caregiver’s home, or by conference call.

As Part of the Consultations, Families Gain:

- An understanding of the disease and what to expect.
- Tips and tools to ensure safety, improve communication, and support management of the behavioral and psychological symptoms of dementia
- Referrals to other experts as needed.

Services offered in English and Spanish

Providence

Current Alzheimer's and Other Related Dementias Resources

Current & Developing Resources:

- Helpline
- Care Consultations
- Support Groups for Caregivers
- Caregiver Dementia Education & Trainings
- Savvy Caregiver Programs
- Powerful Tools For Caregivers
- Early-Stage Programs
- arts4ALZ
- Memory Cafes
- Memory Screenings
- Dementia Care Aware
- Alzheimer's Disease Research Centers
- Alzheimer's Association Programs and Services
- Family Caregiver Resource Centers

Gaps or Missing Services:

- Services for those diagnosed with cognitive decline and living alone
- LTSS resources for people living with dementia and their caregivers
- Affordable care options
- Affordable assisted living memory care facilities
- Support services for middle income caregivers and persons with dementia
- Rural direct care and referral resources
- Direct care programs for persons with a dementia diagnosis

Unaddressed Need:

- Increase number of centers
- Increase capacity of existing centers

Cal-COMPASS

Cal-COMPASS is based on the long tested ADCRC model and conforms with emerging science and national standards for dementia-capable care.

Our goal is to make California a state that is a leader in supporting people living with dementia, as well as their care partners, by providing holistic, culturally-informed direct day program services. To do this, Cal-COMPASS needs to expand to day programs statewide, have expert providers, and be grounded in equity and access.

Aligning Cal-COMPASS with Current Initiatives

The goal is to help individuals living with dementia and caregivers forge a better path forward and meet the related goals of the Master Plan on Aging, Alzheimer's Task Force, and other key efforts:

Master Plan on Aging:

- Goal #2, Health Reimagined (Dementia in Focus);
- Goal #3, Inclusion and Equity, Not Isolation;
- Goal #4, Caregiving that Works; initiative (#66) to assess options to increase adult day services, especially for people with dementia (continued as #43)

Alzheimer's Task Force recommendations:

- #2 on cutting edge research
- #5 on long-term care financing
- #6 on Alzheimer's health care workforce
- #7 on caregiver training
- #10 on a statewide standard of care.

HCBS gap analysis (in process); Caregiver equity road map (in process)

NAPA Update; RAISE plan, Guiding an Improved Dementia Experience (GUIDE) Model

Current Cal-COMPASS Project Sites

1000+ individuals and caregivers are being served through the Cal-COMPASS Project

Providence – Napa County, serving 12 towns/cities (demonstrates what can be built-out from the core model to serve a community's full needs)

OPICA – Los Angeles County

Hearts and Minds – Santa Clara County

Peg Taylor Center – Butte County, also serves Glenn and Tehama Counties

Triple R – Sacramento County

Alzheimer's Family Center – Orange County

Choice in Aging – Contra Costa County: locations in Pleasant Hill and Antioch

Cal-COMPASS Organization-Specific Expected Outcomes

- Expand capacity including language diversity of staff
- Expand enrollment including better representation of community diversity
- Increase awareness, visibility and outreach
- Improve programming – new services/technology
- Increase caregiver support
- Enhance assessment and program evaluation
- Align with Master Plan on Aging objectives

Providence

Restoring the proven ADCRC approach through CAL-COMPASS:

A statewide network of over 50 ADCRC sites was in place until funding was eliminated. Many continued to serve as ADCRCs.

Seven experienced sites are now working with CDA to re-build this comprehensive resource

More than 690,000 individuals in California are currently identified with Alzheimer's disease alone (2020)

Statewide population growth and screening will add substantially to these numbers of people needing direct help.

No other community-based resources that have the expertise and effectiveness of ADCRCs for preventing isolation, increasing engagement, and maintaining improved functioning over time

Providence

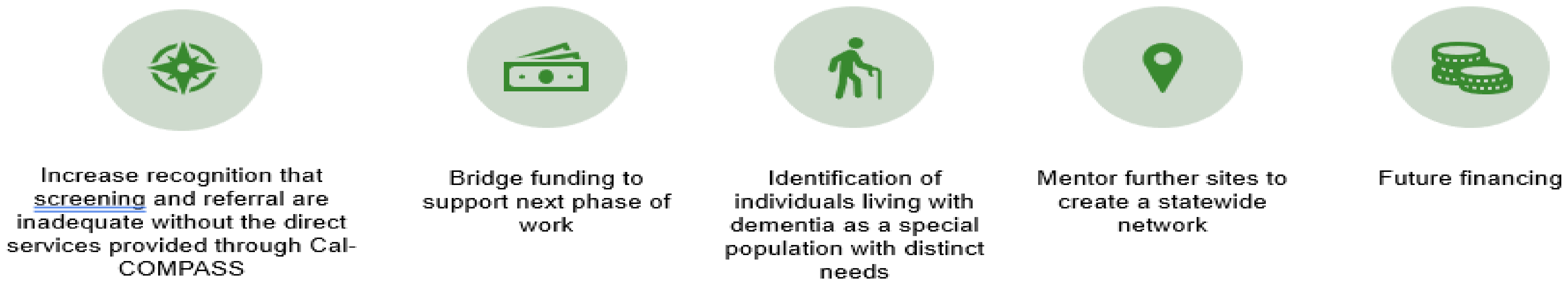
What is the ADCRC/Cal-COMPASS evidence-based model?

- Licensed adult day services programs serve as therapeutic hubs to offer non-pharmacological treatment and support

- A home base where individuals living with dementia of all types can receive direct dementia capable care over time in a deeply person-centered environment, easing depression, anxiety and behavioral symptoms by maintaining identity and connection

- A stable, trusted, long term source of caregiver respite and caregiver support

Cal-COMPASS Next Steps



Increase recognition that screening and referral are inadequate without the direct services provided through Cal-COMPASS

Bridge funding to support next phase of work

Identification of individuals living with dementia as a special population with distinct needs

Mentor further sites to create a statewide network

Future financing

1. Increase recognition that screening and referral are inadequate without the direct services provided through Cal-COMPASS
2. Bridge funding to support next phase of work
3. Identification of individuals living with dementia as a special population with distinct needs
4. Mentor further sites to create a statewide network
5. Future financing

CA Caregiver Resource Centers: Overview

CRC Overview:

Legislative and Service History, Service Model

CA Alzheimer’s and Related Disorders Advisory Committee

November 2023

Presenter for the CRC System

Kathleen Kelly, Director, Family Caregiver Alliance/ Bay Area CRC

History & Background

- CRCs were established in 1984 based on replication of pilot project (1980-83)
- First-in-the-nation statewide network of 11 caregiver resource centers – community-based non-profit agencies
- Modelled, in part, on the Regional Center System: statewide network of community based, non-profits that provide assessment, coordination of internal services, contracts for external services and linkage to other community services that follow clients over time and changing needs, located under a state department

Founded in 1984, the Califor Caregiver Resource Centers are network of 11 centers througho California which serve family caregive who are providing support for someo affected by chronic and debilitatin health conditions including dementi Alzheimer's disease, cerebrovascula diseases (such as stroke or aneurysms) degenerative diseases such as Parkinson's Huntington's and multiple sclerosis, or traumatic brain injury (TBI), among many others.

Caring for a loved one with a cognitive disorder or another disabling condition forever changes the lives of families and caregivers. There can be devastating effects on those providing long-term care: financial pressures, legal quandaries, health problems, and emotional turmoil.

Fortunately, the California Caregiver Resource Centers offer **FREE** support throughout the state, serving thousands of families and caregivers across income categories. Every California resident has access to a CRC in their area. The CRCs are united by shared values emphasizing choice, collaboration, innovation, quality, participation, respect & diversity.

For more information on the California Caregiver Resource Centers, visit:

www.caregivercalifornia.org

> "I have benefited so much from the services the California CRCs have provided, especially the counseling and respite care. They gave me guidance and hope during very difficult times."
>
> – *Family Caregiver*

CALIFORNIA caregiver
Resource Centers
Educate. Connect. Support.

Resources for families and caregivers of adults with chronic, disabling health conditions.

www.caregivercalifornia.org

Los Angeles Caregiver Resource Center
(800) 540-4442
E-mail: fcscgero@usc.edu
Website: www.fcscgero.org
Serving: Los Angeles County

Caregiver Resource Center OC
(800) 543-8312
E-mail: ocrcuser@stjoe.org
Website: www.caregiveroc.org
Serving: Orange County

Passages Caregiver Resource Center
(530) 898-5925
E-mail: passages@csuchico.edu
Website: www.caregiverresources.org
erving: Butte, Glenn, Lassen, Modoc, Plumas, hasta, Siskiyou, Tehama, and Trinity Counties

edwood Caregiver Resource Center
00) 834-1636
mail: rcrc@redwoodcrc.org
ebsite: www.redwoodcrc.org
ving: Del Norte, Humboldt, Lake, Mendocino, a, Solano & Sonoma Counties

thern Caregiver Resource Center
) 268-4432 or (800) 827-1008
il: scrc@caregivercenter.org
ite: www.caregivercenter.org
g: Imperial & San Diego Counties

y Caregiver Resource Center
41-8614
info@valleycrc.org
e: www.valleycrc.org
Fresno, Kern, Kings, Madera, Mariposa, Stanislaus, Tulare & Tuolumne Counties

History and Background

The CRCs had distinct characteristics since its inception in 1984:

- Defined package of services administered by all CRCs statewide
- Target unpaid family caregivers of persons with Alzheimer’s and related dementias, Parkinson’s, head injuries, stroke, and other adult-onset cognitive impairments and chronic health conditions over the care journey
- Serve all income groups including the “missing middle income”
- Use uniform intake and assessment covering multiple domains of caregiver assessment and care receiver information
- Provide education and training for onboarding staff; identify key training for staff development
- Collect and use data for site specific knowledge and change; use data on statewide level to measure impact, change in populations and problems identified and drive quality improvements across system; disseminate Annual Report

Service Model

CRC Service Package:

- Uniform Intake & Assessment
- Care Plan & Consultation
- Counseling (short-term)
- Legal and Financial Information and Consultation
- Respite Vouchers (including consumer-directed choice and options)
- Psychoeducational interventions
- Professionally-led support groups
- Linkage to other community resources

Service Model

CRC Service Package:

- Specialized training for direct care issues
- Education programs
- State and regional training calendars for classes for anyone/anywhere (50K list)
- Monthly consumer/caregiver newsletters

Consumer Information and Content (400+) including (& tagged to assessment):

- Fact Sheets & Tip Sheets & Checklists
- Video clips on direct care, medical tasks and management
- Webinar archives
- For most used/requested Fact Sheets, with translations: 72 Spanish; 60 Chinese; 40 Vietnamese; 25 Tagalog Many classes, videos and webinars are in other languages

History and Background

In 2019, the CRCs advocated for a budget augmentation to:

- Increase service delivery and cross-CRC collaboration
- Deploy a statewide interactive client record system and secure online portal for caregivers
- Increase use of technologies to extend services
- Promote quality practice and standardization of core services
- Collect data and contract for yearly evaluation report; contract for statewide outreach activities and visibility for family caregivers and CRC services

Project Overview:

Scaling Services to a Changing Caregiver Population

CA state investment: CA Department of Health Care Services awarded the eleven CRCs $30 million ($10M/yr; $15M total appropriation) to expand services and enhance technology services (2019- 2022)**

Technologies & Practice Change

- CareNav install & client-facing portal
- Communication Technologies i.e. Zoom Health Platform or similar secure product for individual telehealth (e-consult) encounters or small group counseling/support groups + digital marketing capabilities
- Training for staff on CareNav, communication technologies and changed practice standards
- Statewide evaluation and outreach

**$30M expansion funding made permanent in 2021 budget process @ $10M/yr; $15M/yr total appropriation

What is CareNav?

- Cloud-based, HIPAA-compliant client record system
- Family caregiver can open their own record & start intake
- Client dashboard with multiple functionalities
- Admin backend for data entry, service data, reports for payment sources
- Real-time data for site usage, for client, data export capabilities, internal operations
- FCA Use Case: CRC, National, NIH COPE PD, Cgr Services Partner, Community Practice, Neurology, Parkinson’s/Lewy Body Care Partner/Caregiver; NIA, WECARE, USC Keck Medical Center, Elder Abuse Prevention Intervention

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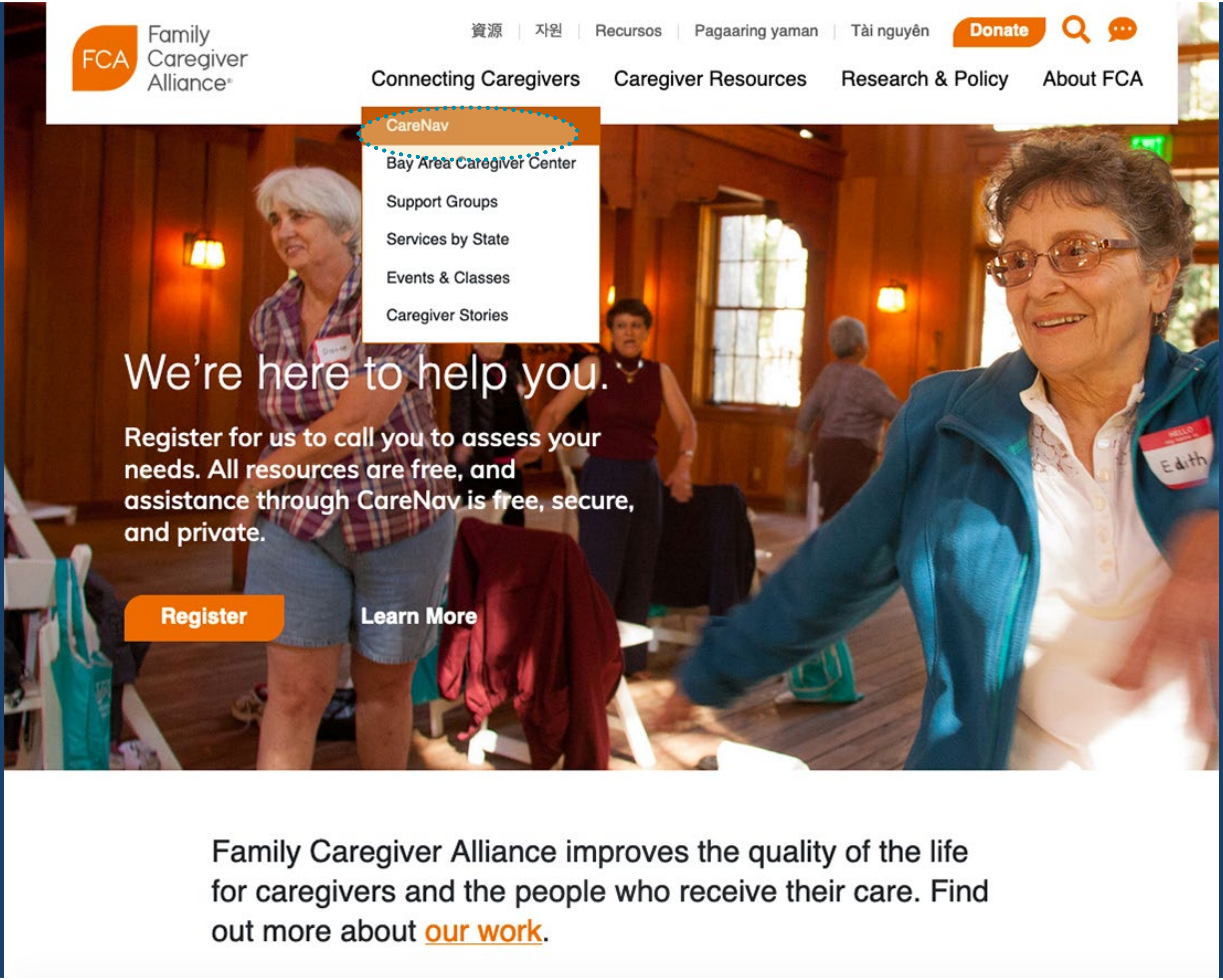
Family Caregiver Alliance Website

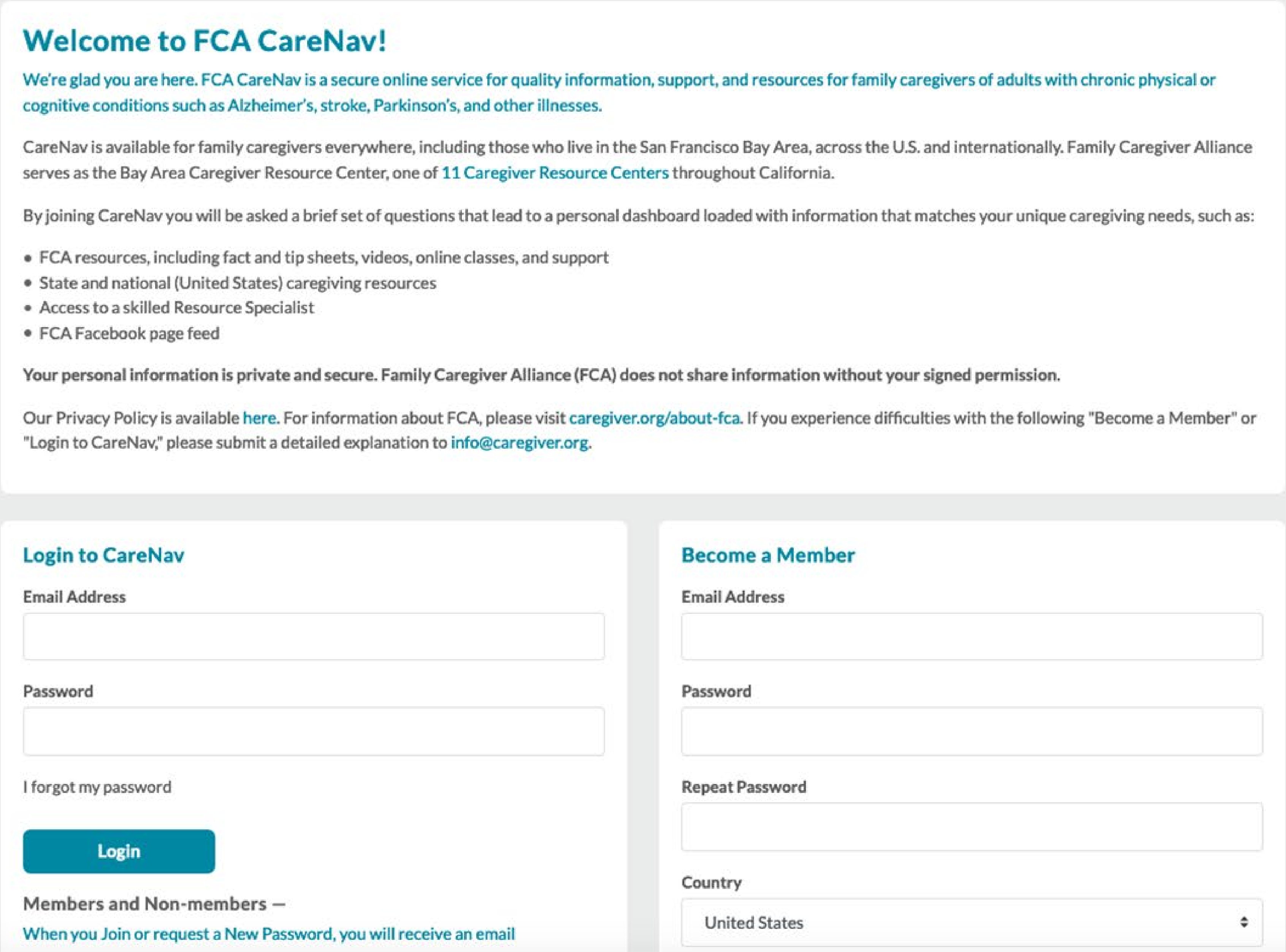


We're here to help you.

Register for us to call you to assess your needs. All resources are free, and assistance through CareNav is free, secure, and private.

Family Caregiver Alliance improves the quality of the life for caregivers and the people who receive their care. Find out more about our work.

FCA CareNav



Welcome to FCA CareNav!

We're glad you are here. FCA CareNav is a secure online service for quality information, support, and resources for family caregivers of adults with chronic physical or cognitive conditions such as Alzheimer's, stroke, Parkinson's, and other illnesses.

CareNav is available for family caregivers everywhere, including those who live in the San Francisco Bay Area, across the U.S. and internationally. Family Caregiver Alliance serves as the Bay Area Caregiver Resource Center, one of 11 Caregiver Resource Centers throughout California.

By joining CareNav you will be asked a brief set of questions that lead to a personal dashboard loaded with information that matches your unique caregiving needs, such as:

- FCA resources, including fact and tip sheets, videos, online classes, and support
- State and national (United States) caregiving resources
- Access to a skilled Resource Specialist
- FCA Facebook page feed

Your personal information is private and secure. Family Caregiver Alliance (FCA) does not share information without your signed permission.

Our Privacy Policy is available here. For information about FCA, please visit caregiver.org/about-fca. If you experience difficulties with the following "Become a Member" or "Login to CareNav," please submit a detailed explanation to info@caregiver.org.

Login to CareNav

Email Address

Password

Members and Non-members —

When you Join or request a New Password, you will receive an email

Become a Member

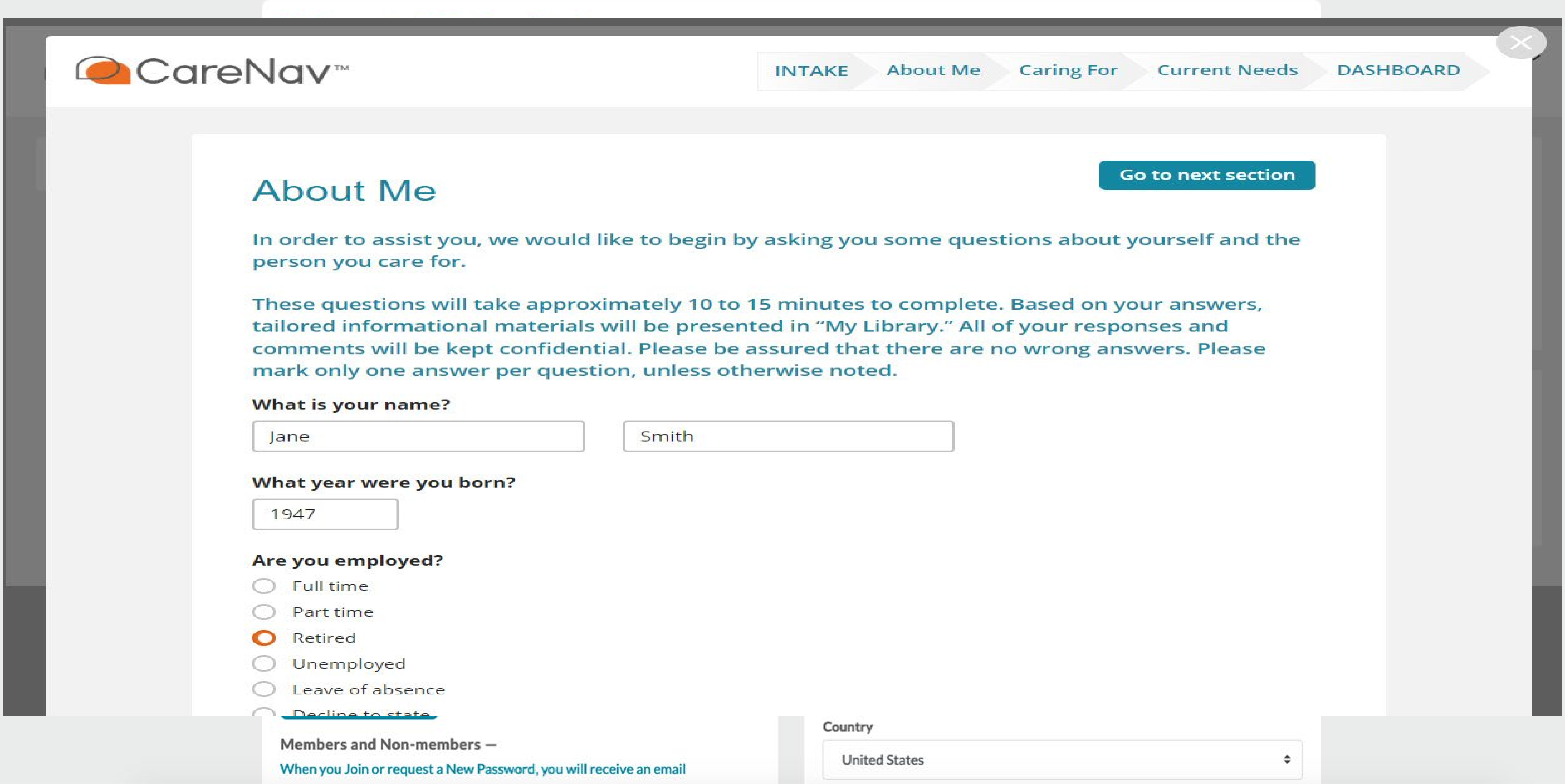
Email Address

Password

Repeat Password

Country: United States

CareNav About Me Section



About Me

In order to assist you, we would like to begin by asking you some questions about yourself and the person you care for.

These questions will take approximately 10 to 15 minutes to complete. Based on your answers, tailored informational materials will be presented in "My Library." All of your responses and comments will be kept confidential. Please be assured that there are no wrong answers. Please mark only one answer per question, unless otherwise noted.

What is your name?

Jane Smith

What year were you born?

1947

Are you employed?

○ Full time
○ Part time
● Retired
○ Unemployed
○ Leave of absence
○ Decline to state

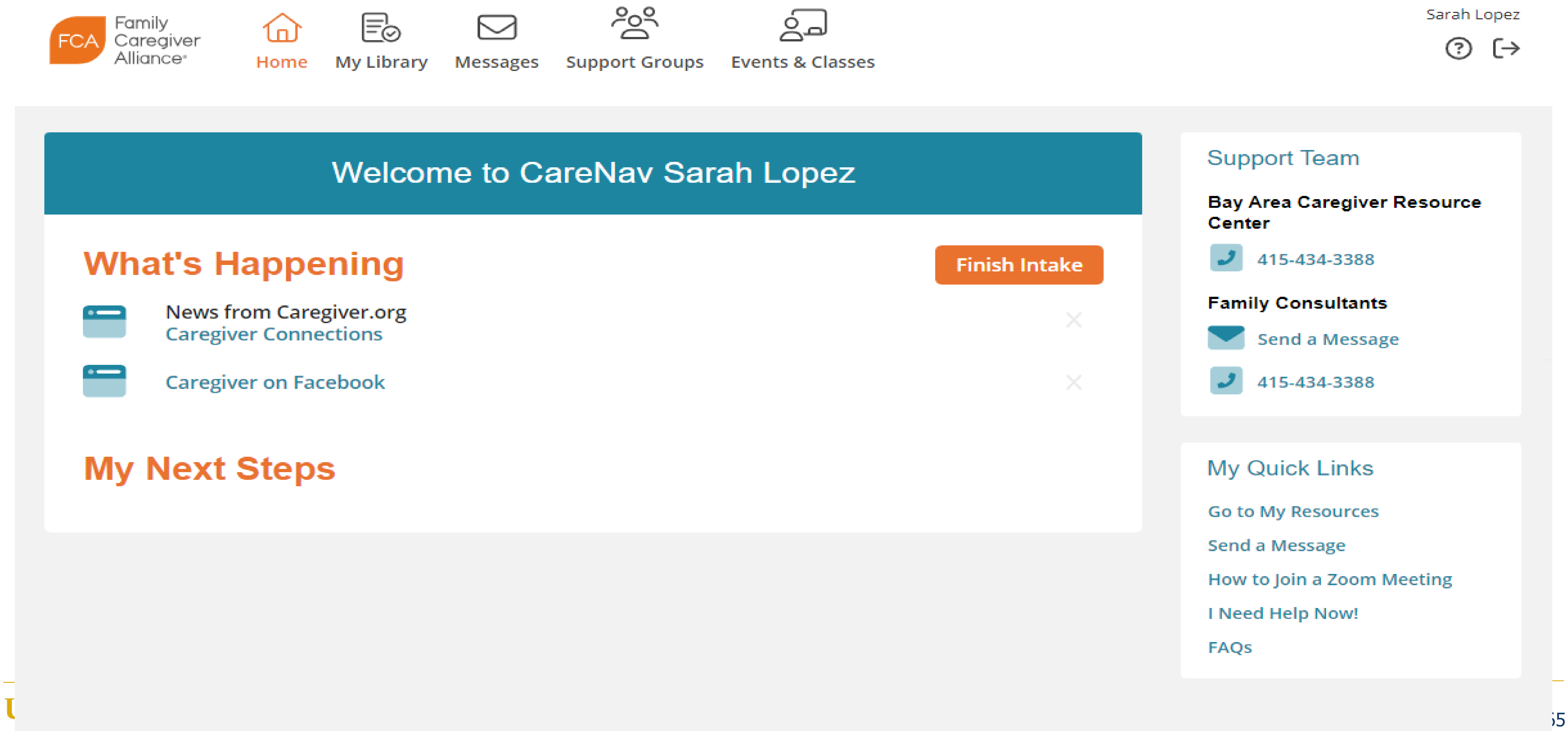
Members and Non-members —

When you Join or request a New Password, you will receive an email

Country

United States

CareNav Profile Page



Welcome to CareNav Sarah Lopez

What's Happening

News from Caregiver.org
Caregiver Connections

Caregiver on Facebook

My Next Steps

Support Team

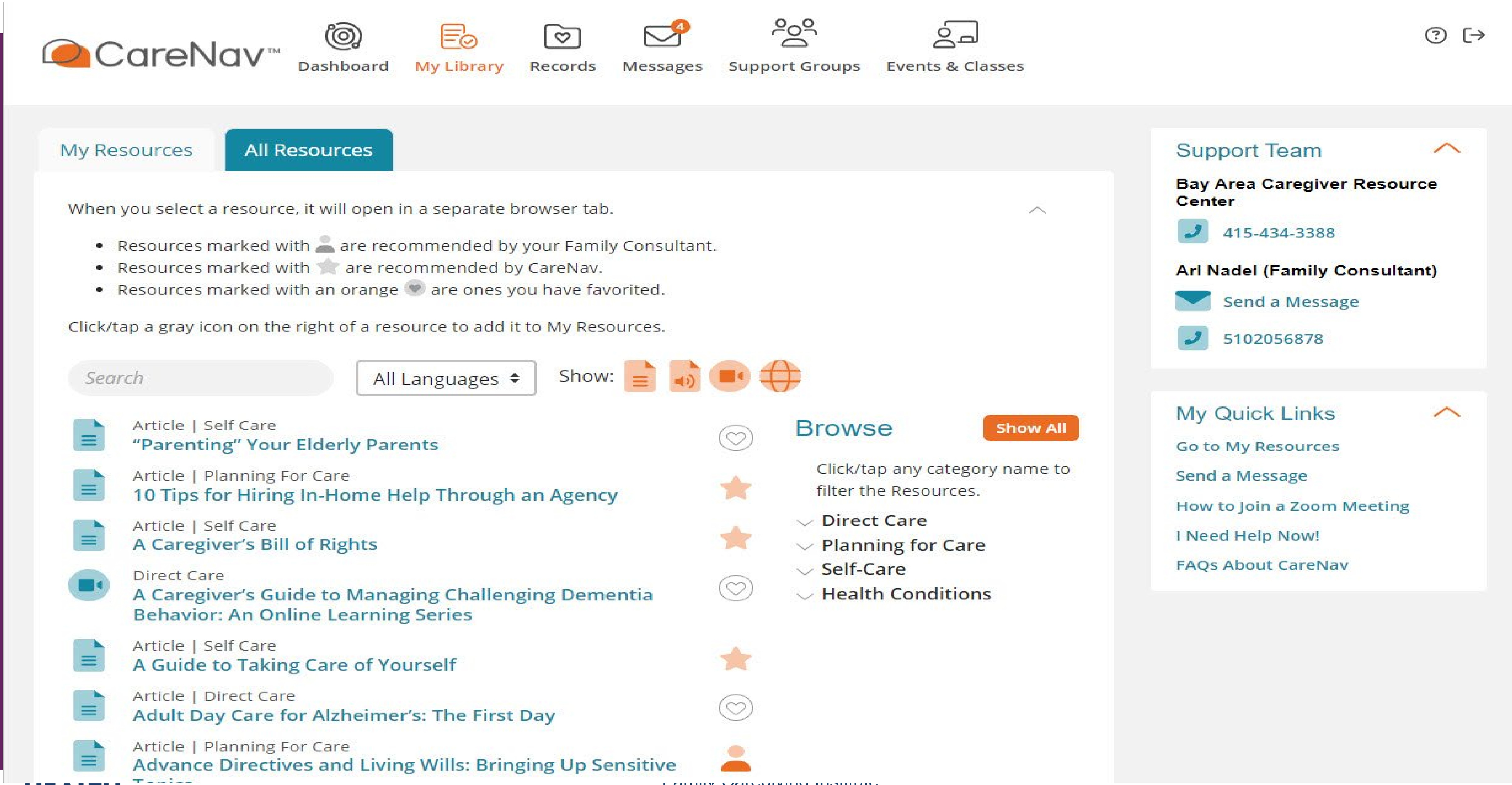
Bay Area Caregiver Resource Center
☎ 415-434-3388

Family Consultants
✉ Send a Message
☎ 415-434-3388

My Quick Links

- Go to My Resources
- Send a Message
- How to Join a Zoom Meeting
- I Need Help Now!
- FAQs

CareNav Resource Page



When you select a resource, it will open in a separate browser tab.

- Resources marked with 👤 are recommended by your Family Consultant.
- Resources marked with ★ are recommended by CareNav.
- Resources marked with an orange ♡ are ones you have favorited.

Click/tap a gray icon on the right of a resource to add it to My Resources.

Search

All Languages

Article | Self Care
"Parenting" Your Elderly Parents

Article | Planning For Care
10 Tips for Hiring In-Home Help Through an Agency

Article | Self Care
A Caregiver's Bill of Rights

Direct Care
A Caregiver's Guide to Managing Challenging Dementia Behavior: An Online Learning Series

Article | Self Care
A Guide to Taking Care of Yourself

Article | Direct Care
Adult Day Care for Alzheimer's: The First Day

Article | Planning For Care
Advance Directives and Living Wills: Bringing Up Sensitive

Browse

Click/tap any category name to filter the Resources.

- Direct Care
- Planning for Care
- Self-Care
- Health Conditions

Support Team

Bay Area Caregiver Resource Center

415-434-3388

Ari Nadel (Family Consultant)

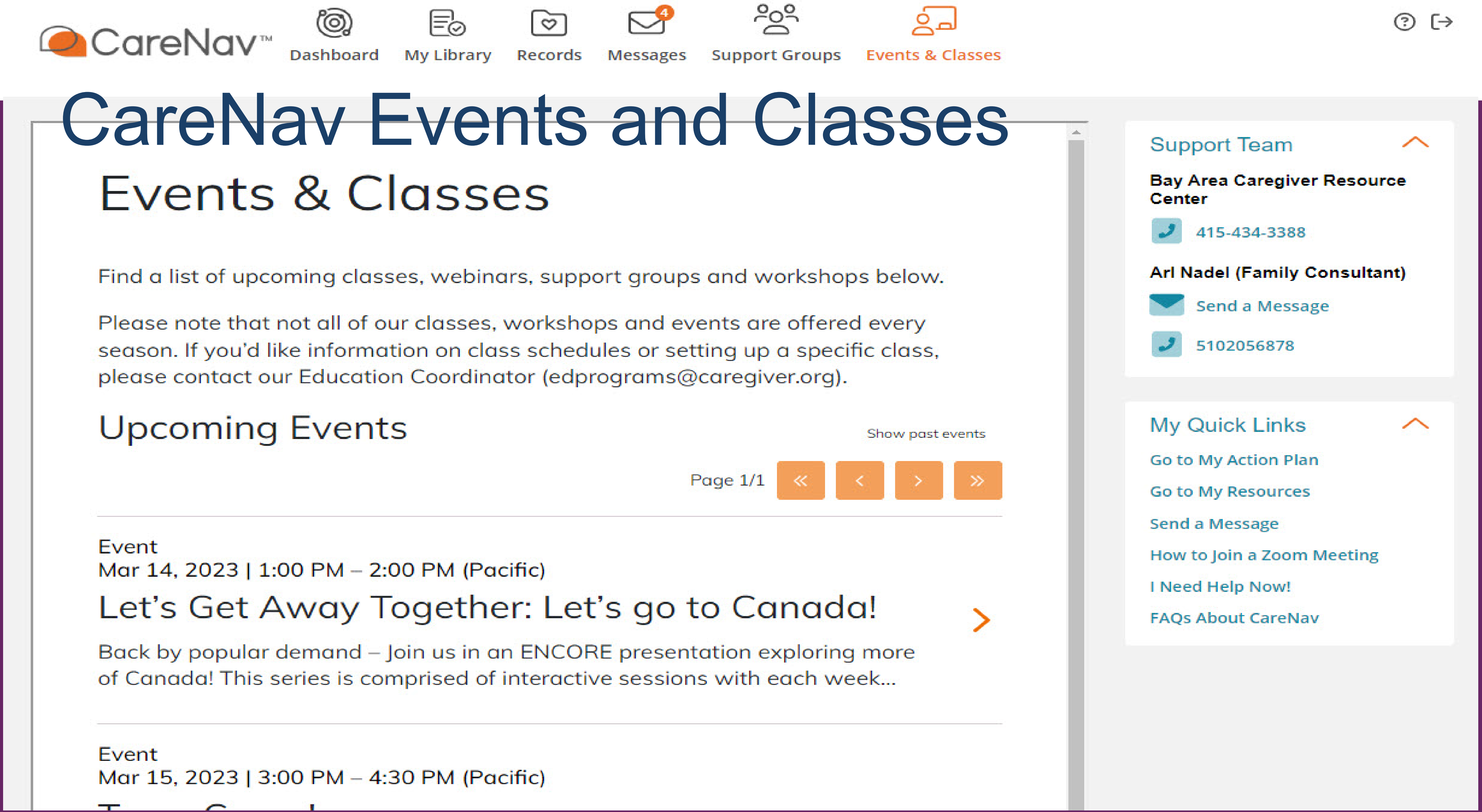
Send a Message

5102056878

My Quick Links

Go to My Resources
Send a Message
How to Join a Zoom Meeting
I Need Help Now!
FAQs About CareNav

CareNav Events and Classes



Events & Classes

Find a list of upcoming classes, webinars, support groups and workshops below.

Please note that not all of our classes, workshops and events are offered every season. If you'd like information on class schedules or setting up a specific class, please contact our Education Coordinator (edprograms@caregiver.org).

Upcoming Events

Event
Mar 14, 2023 | 1:00 PM – 2:00 PM (Pacific)

Let's Get Away Together: Let's go to Canada!

Back by popular demand – Join us in an ENCORE presentation exploring more of Canada! This series is comprised of interactive sessions with each week...

Event
Mar 15, 2023 | 3:00 PM – 4:30 PM (Pacific)

Support Team

Bay Area Caregiver Resource Center
☎ 415-434-3388

Arl Nadel (Family Consultant)
Send a Message
☎ 5102056878

My Quick Links

- Go to My Action Plan
- Go to My Resources
- Send a Message
- How to Join a Zoom Meeting
- I Need Help Now!
- FAQs About CareNav

Next steps: CRC System

- Increase reach into diverse communities
- Assure quality:
  - staff expertise & consistent practice standards
  - data collection
  - use data to identify/target high-need service areas

Questions

Contact Information:
Kathleen Kelly, MPA, Executive Director
kkelly@caregiver.org

Caregiver Behavioral Health: An Overview

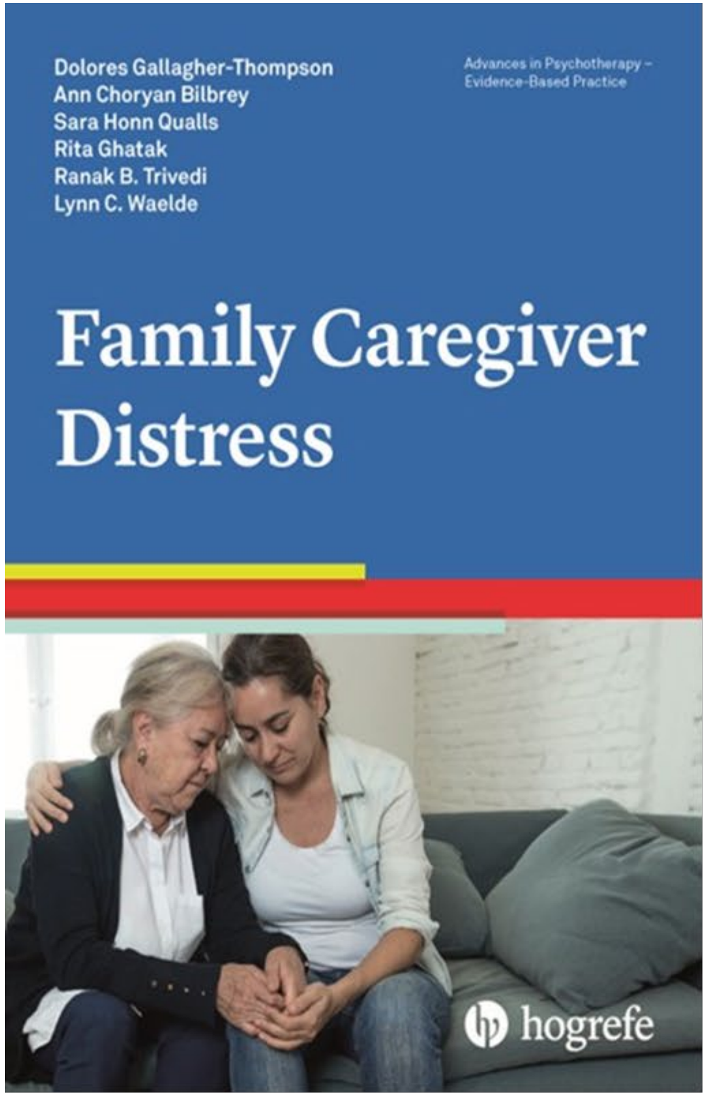
Dolores Gallagher-Thompson, PhD, ABPP – Board Certified Geropsychologist
Research Professor Emerita, Stanford University School of Medicine;
Co-Founder, Optimal Aging Center, Sunnyvale, CA

California Department of Aging: Alzheimer's Disease and Related Disorders
Advisory Committee Meeting, November 2, 2023

OPTIMAL AGING CENTER

Stanford MEDICINE

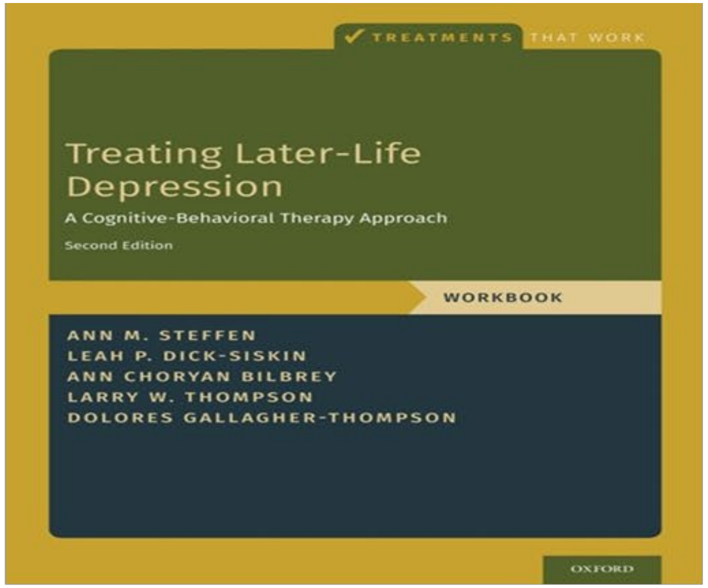
Books that Expand on Behavioral Health Interventions for Distressed Caregivers


Dolores Gallagher-Thompson
Ann Choryan Bilbrey
Sara Honn Qualls
Rita Ghatak
Ranak B. Trivedi
Lynn C. Waelde

Advances in Psychotherapy – Evidence-Based Practice

Family Caregiver Distress

hogrefe

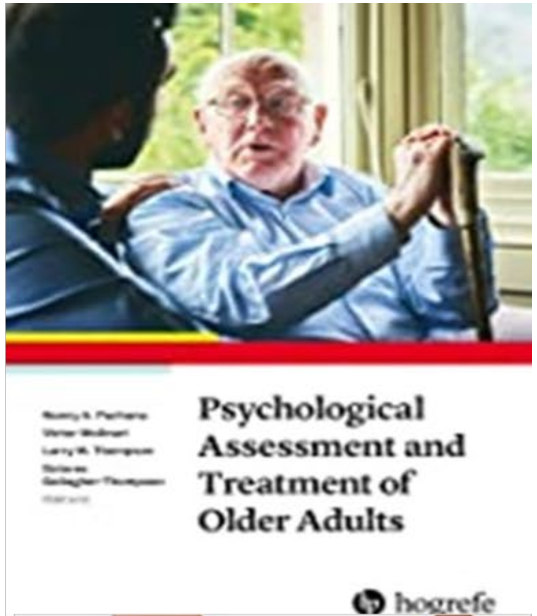

TREATMENTS THAT WORK

Treating Later-Life Depression
A Cognitive-Behavioral Therapy Approach
Second Edition

WORKBOOK

ANN M. STEFFEN
LEAH P. DICK-SISKIN
ANN CHORYAN BILBREY
LARRY W. THOMPSON
DOLORES GALLAGHER-THOMPSON

OXFORD


Psychological Assessment and Treatment of Older Adults

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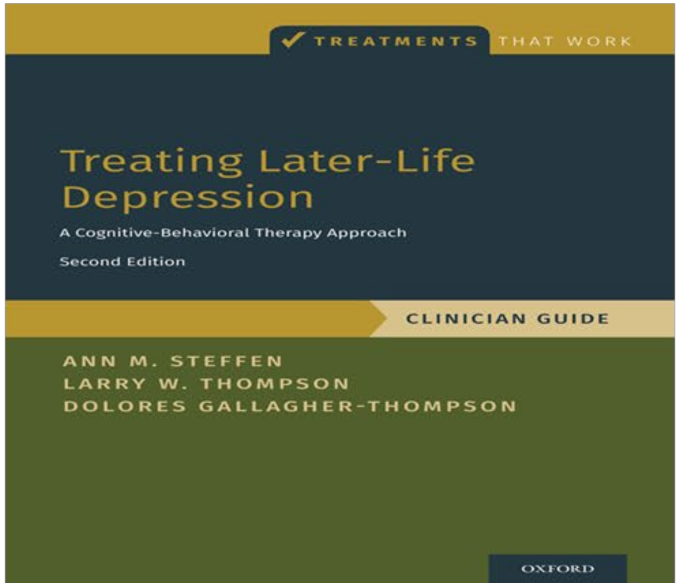
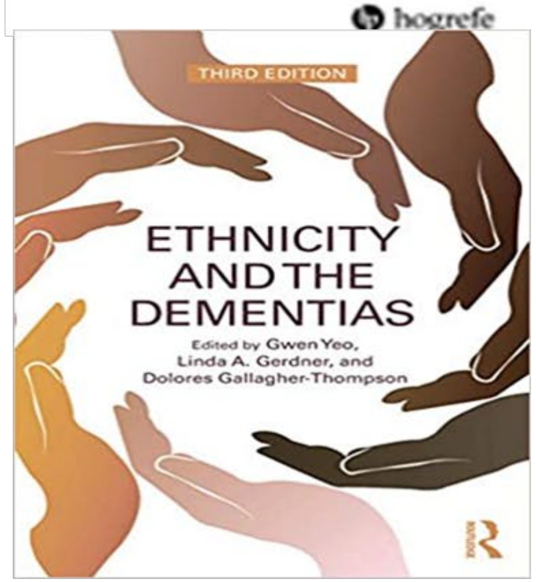

TREATMENTS THAT WORK

Treating Later-Life Depression
A Cognitive-Behavioral Therapy Approach
Second Edition

CLINICIAN GUIDE

ANN M. STEFFEN
LARRY W. THOMPSON
DOLORES GALLAGHER-THOMPSON

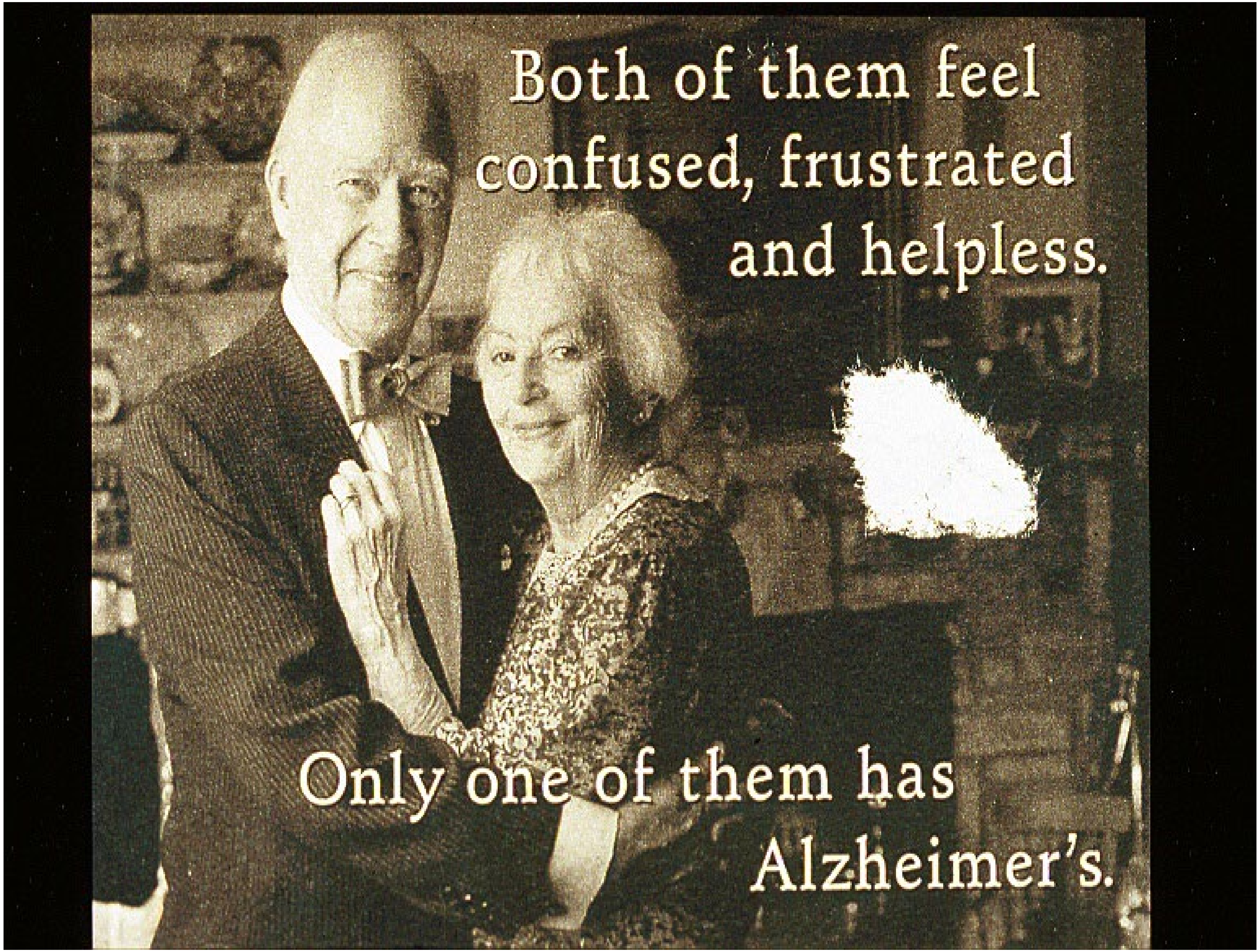
OXFORD


THIRD EDITION

ETHNICITY AND THE DEMENTIAS

Edited by Gwen Yeo, Linda A. Gerdner, and Dolores Gallagher-Thompson

Both of them feel confused, frustrated and helpless. Only one of them has Alzheimer’s.



Caregivers - The Hidden Patient

AT RISK FOR:

- **Depression -40-50% caregivers are significantly depressed**
- **Many suffer with high stress levels, feelings of being overwhelmed, and fears/ anxieties regarding the future**
- **Other negative feelings (guilt, frustration, inadequacy, resentment, and feeling exhausted) are also common**
- **Social isolation and loneliness increase over time**
- **Financial strain often results from caregivers having to quit their jobs or significantly reduce their work hours**

Snapshot of Caregivers' Mental Health -based on data from National Alliance for Caregiving and AARP – May 2020

- **4 in 10** caregivers experience high emotional strain
- **Emotional or mental health issues** are more often reported by those:
  - who care for someone 50 years or older
  - serve as a primary caregiver or partner
  - care for someone with a long-term physical condition
- Almost three quarters (74%) of caregivers **feel alone**
- **Women** report experiencing higher stress compared to men
- Levels of emotional distress **vary by race/ethnicity**:
  - Asian Americans (42%)
  - African Americans (31%)
  - Latinos (28%)

National Alliance for Caregiving Spotlight on Mental Health October 2023

Caregiving has both negative and positive effects

- Stress
- Burden
- Depression
- Anxiety
- Cognitive Problems
- Physical Health Issues

(Alz Assn 2022)

Positive Aspects of Caregiving

Reported Rewards

- Giving back
- Higher quality of care
- Personal growth
- Life meaning and purpose
- Passing on a family tradition of care
- Modeling caregiving for their children

Cognitive Benefits

- Sharpen the CG's mind and improve memory

Physical Benefits

- Daily Physical Activity builds strength & stamina

Mood Benefits

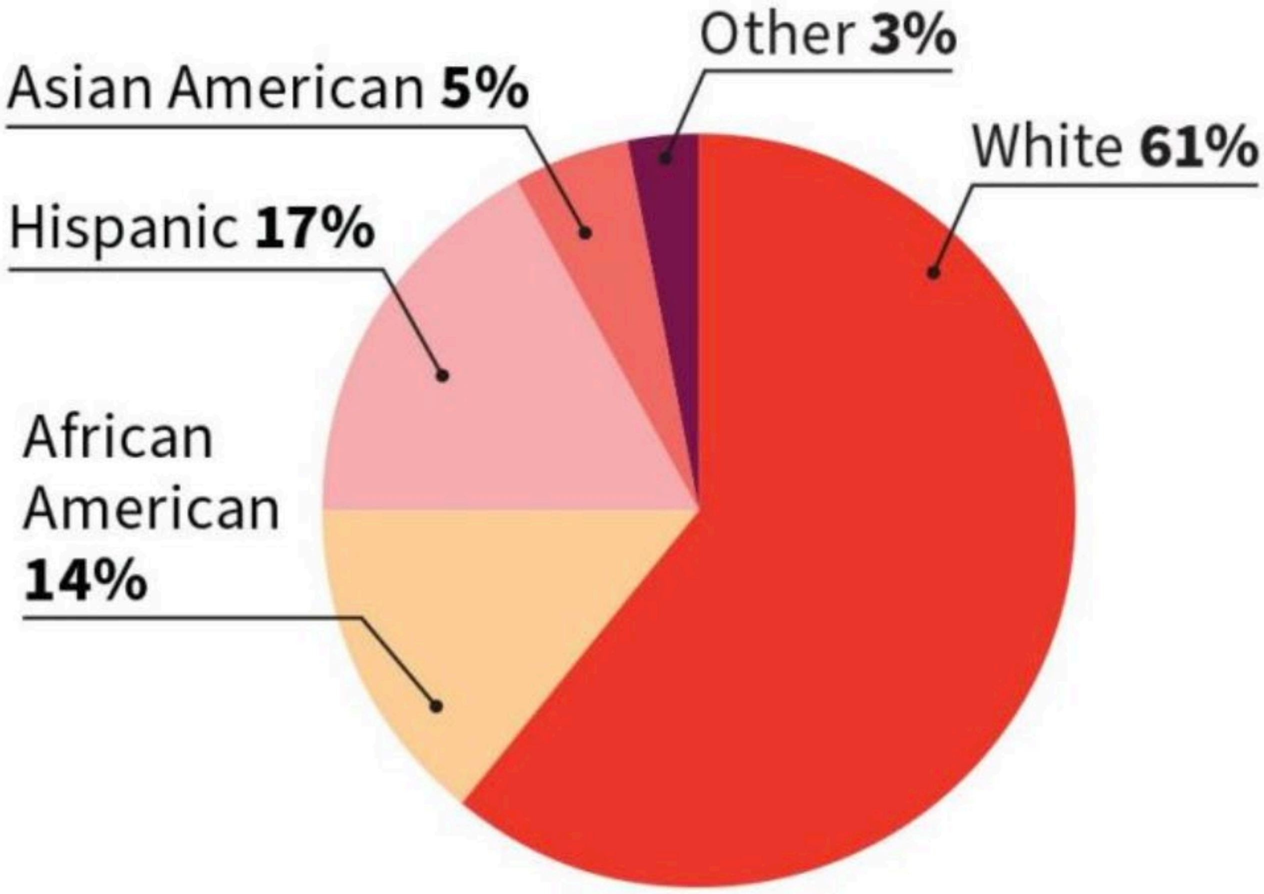
- Caregivers who experience positive aspects of caregiving show lower levels of depression

(Alz Assn 2022)

What Causes Caregiving to be Stressful?

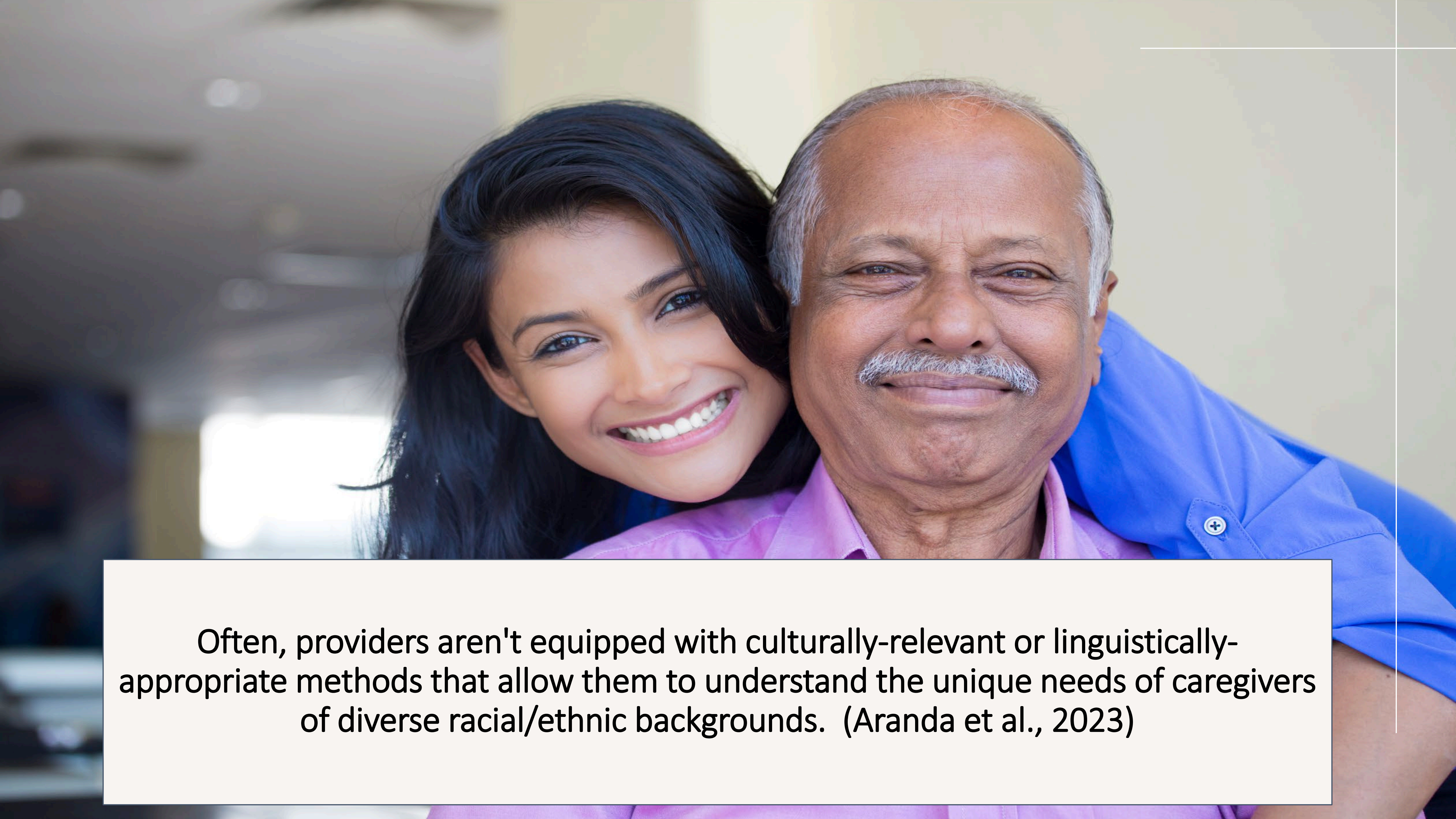
- Lack of control & predictability
- Increasing social isolation
- Perception that things are getting worse
- Feelings of helplessness

Diversity in Caregiving



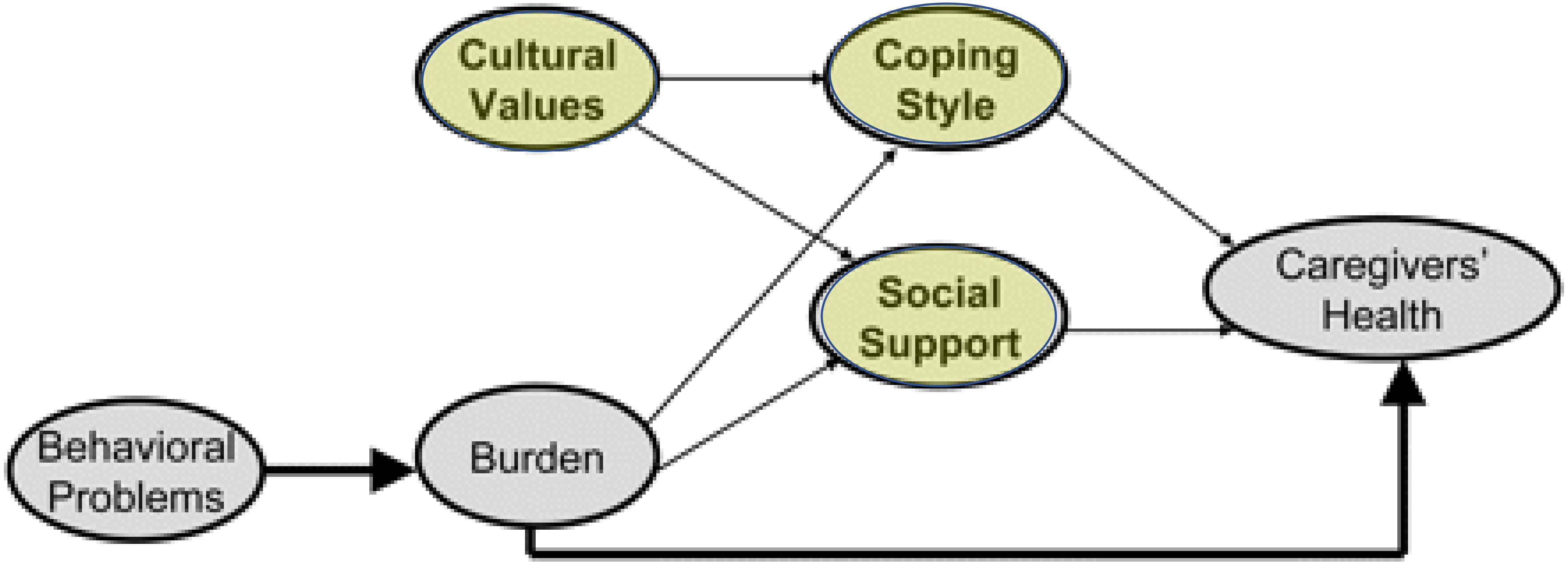
9% of family caregivers identify as LGBTQ+

AARP PUBLIC POLICY INSTITUTE



Often, providers aren't equipped with culturally-relevant or linguistically-appropriate methods that allow them to understand the unique needs of caregivers of diverse racial/ethnic backgrounds. (Aranda et al., 2023)

Contributions of Cultural Values, Beliefs, and Practices to Caregiving Stress



Cultural Values

Coping Style

Social Support

Caregivers' Health

Behavioral Problems

Burden

Note. The revised sociocultural stress and coping model presented here includes only key variables, with 3 key factors that vary across cultural groups presented in color. Reproduced with permission from Knight and Sayegh (2010).

Considering the Sociocultural Context

- **Sociocultural influences can shape:**
  - signs and symptoms of caregiver distress
  - caregivers’ understanding of their feelings, thoughts, behavior views of others and the environment
  - help-seeking behaviors and the kinds of treatments / interventions that are considerable acceptable and reasonable

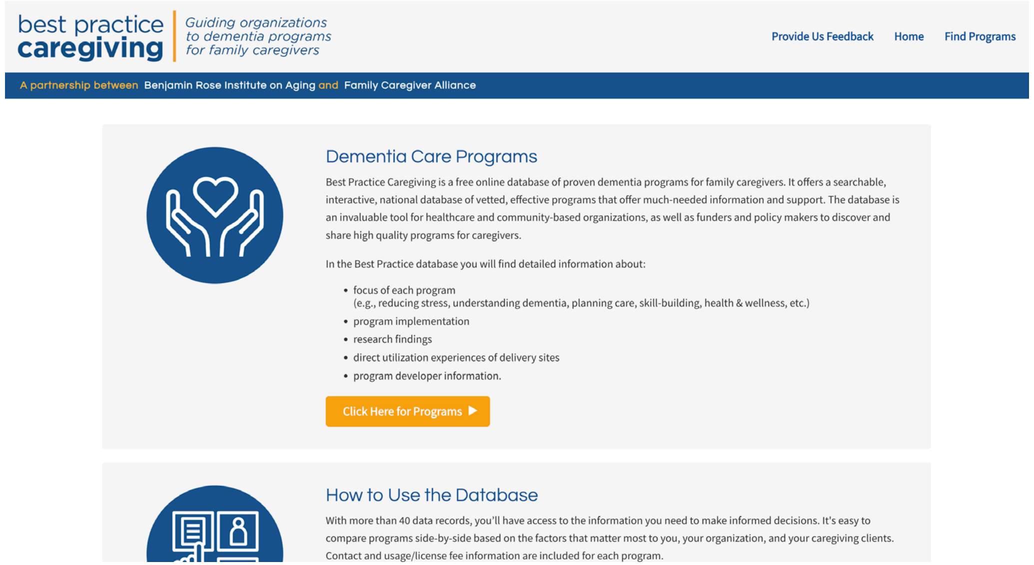
- **Sociocultural context can also create additional barriers:**
  - language barriers, culturally insensitive services, financial constraints
  - Providers bring their own sociocultural history to their interactions with family caregivers which may or may not facilitate good communication with them

(Yeo, Gerdner & Gallagher-Thompson, 2018)

Great Resource to Locate Evidence-Based Interventions for Dementia Family Caregivers: Best Practice Caregiving Registry

Best Practice Caregiving

partnership between Benjamin Rose Institute of Aging and Family Caregiver Alliance – registry of evidence-based programs for caregivers



Dementia Care Programs

Best Practice Caregiving is a free online database of proven dementia programs for family caregivers. It offers a searchable, interactive, national database of vetted, effective programs that offer much-needed information and support. The database is an invaluable tool for healthcare and community-based organizations, as well as funders and policy makers to discover and share high quality programs for caregivers.

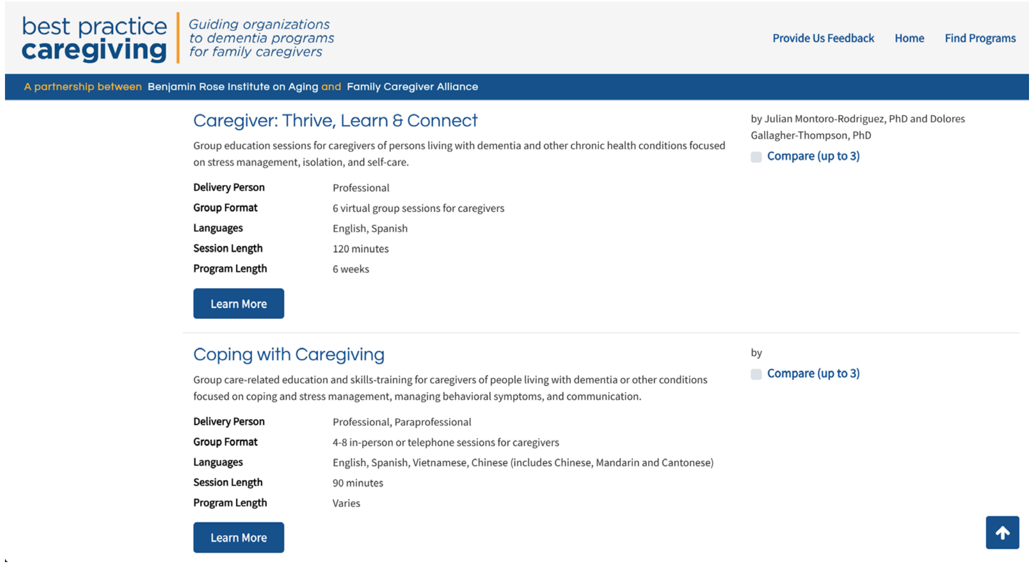
In the Best Practice database you will find detailed information about:

- focus of each program
  (e.g., reducing stress, understanding dementia, planning care, skill-building, health & wellness, etc.)
- program implementation
- research findings
- direct utilization experiences of delivery sites
- program developer information.

How to Use the Database

With more than 40 data records, you'll have access to the information you need to make informed decisions. It's easy to compare programs side-by-side based on the factors that matter most to you, your organization, and your caregiving clients. Contact and usage/license fee information are included for each program.

https://bpc.caregiver.org/#home



Caregiver: Thrive, Learn & Connect

by Julian Montoro-Rodriguez, PhD and Dolores Gallagher-Thompson, PhD

☐ Compare (up to 3)

Group education sessions for caregivers of persons living with dementia and other chronic health conditions focused on stress management, isolation, and self-care.

Delivery Person	Professional
Group Format	6 virtual group sessions for caregivers
Languages	English, Spanish
Session Length	120 minutes
Program Length	6 weeks

Coping with Caregiving

by

☐ Compare (up to 3)

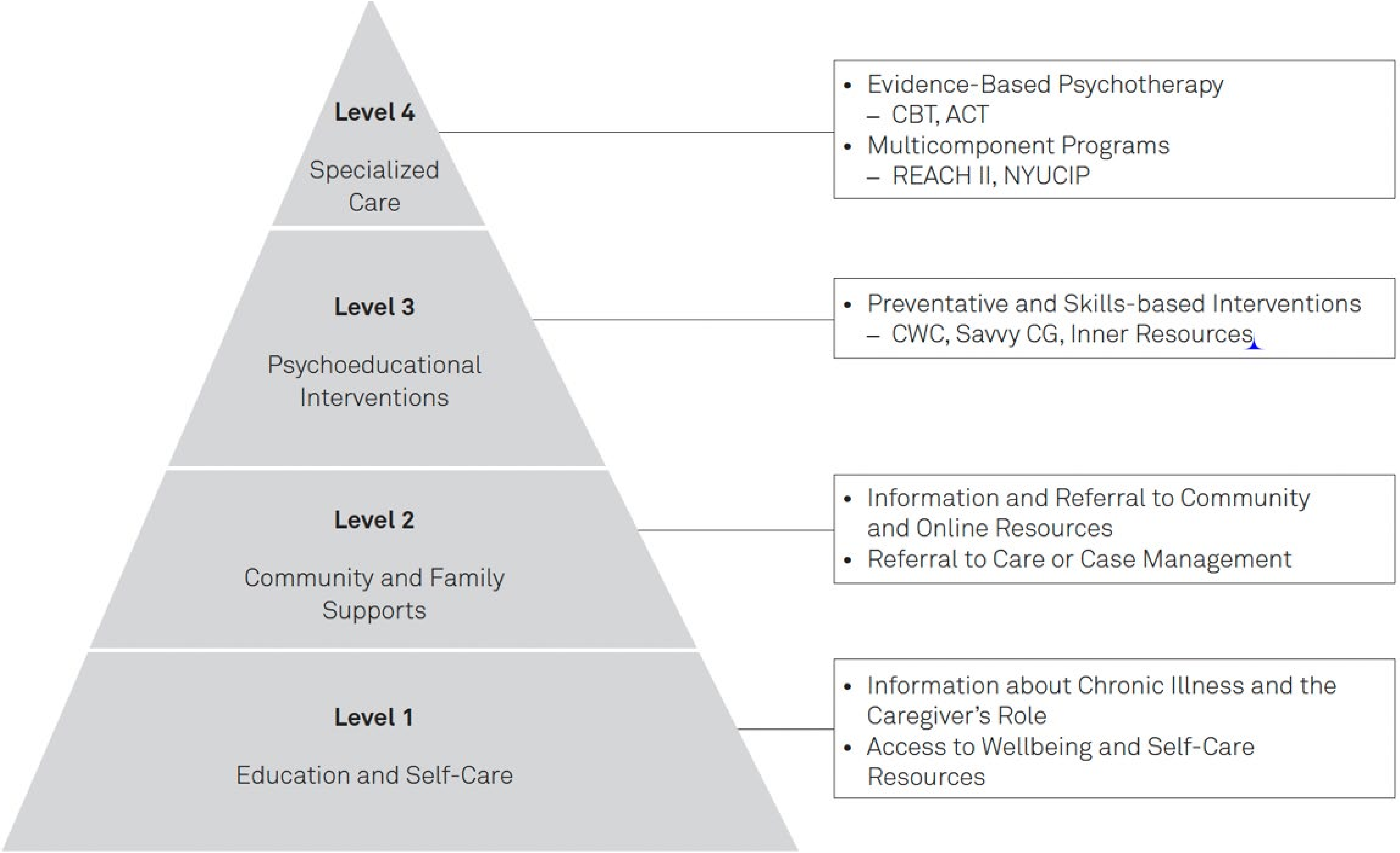
Group care-related education and skills-training for caregivers of people living with dementia or other conditions focused on coping and stress management, managing behavioral symptoms, and communication.

Delivery Person	Professional, Paraprofessional
Group Format	4-8 in-person or telephone sessions for caregivers
Languages	English, Spanish, Vietnamese, Chinese (includes Chinese, Mandarin and Cantonese)
Session Length	90 minutes
Program Length	Varies

https://bpc.caregiver.org/#searchPrograms

Stepped Approach

- Advances in Psychotherapy- Evidence-Based Practice: Family Caregiver Distress



Level 4

Specialized Care

- Evidence-Based Psychotherapy
  - CBT, ACT
- Multicomponent Programs
  - REACH II, NYUCIP

Level 3

Psychoeducational Interventions

- Preventative and Skills-based Interventions
  - CWC, Savvy CG, Inner Resources

Level 2

Community and Family Supports

- Information and Referral to Community and Online Resources
- Referral to Care or Case Management

Level 1

Education and Self-Care

- Information about Chronic Illness and the Caregiver's Role
- Access to Wellbeing and Self-Care Resources

Note: Ascending levels of the intervention pyramid represent increasingly specialized supports that are needed by smaller proportions of the caregiver population. All levels of intervention are important and may be used concurrently. It is likely that a linear progression from bottom to top will not occur. Recommendation is to view all levels when making a determination on best use of interventions based on CG needs.

OPTIMAL AGING CENTER

Gallagher-Thompson, D., Bilbrey, A. C., Qualls, S. H., Ghatak, R., Trivedi, R., & Waelde, L. C. (2023). *Family Caregiver Distress*. Hogrefe Publishing.

Stanford MEDICINE

Trajectory of Caregiving

(Adapted from Gallagher Thompson et al., 2020)

Caregiver and Care Recipient's Culture Sets the Context for the Caregiving Trajectory

	Early Stage	Transition	Middle Stage	Transition	Late Stage
Care Recipient	▪ CR diagnosis ▪ Outpatient Care ▪ Wellness Focus ▪ Slowing down decline ▪ Stabilization	▪ Increased interaction between CR & HCS	▪ Escalation of: Medical care Behavioral issues Dependence on CG	▪ Increased interaction between CR & HCS	▪ Total dependence on CG ▪ Possible move to LTC ▪ Palliative/ EOL Care
Caregiver	▪ Conscious adoption of role ▪ Denial, grief, conflict ▪ Information seeking ▪ HCS interface ▪ CR advocacy ▪ Care planning ▪ Family planning	▪ Increased dependency resulting in adjustments to social & work life	▪ Increased responsibility for all decision making ▪ Changes in CG mental & physical health ▪ CR/CG relationship changes ▪ Anticipatory grief	▪ Higher burden & strain affecting mental & physical health	▪ Decision to remain in home or move to LTC ▪ Anticipatory grief ▪ Bereavement, sadness, relief ▪ Adjustment to life after caregiving
Health System Interventions	▪ CR assessment, diagnosis ▪ CG strengths & vulnerabilities assessment ▪ Education/coping skills	▪ Increased utilization of HCS	▪ Medical care for co-morbidities ▪ Training for at-home nursing tasks ▪ Continued care planning ▪ Case management	▪ Increased utilization of HCS	▪ Support for EOL care ▪ Balancing selfcare & care tasks ▪ Support groups

Culture includes both their Heritage and the Health Systems Culture they interact with

Brief Assessments

In order to understand basic mental health needs of clients, we recommend that providers administer these 3 self-report questionnaires that are available in other languages and take about 10 minutes to complete. There are also on-line versions available if preferred.

1. ***PHQ-2 to screen for depression****. Follow up with PHQ-9 if indicated. There are established cut-off scores to help clinicians decide what kind of intervention is needed – e.g. "watchful waiting" vs. psychotherapy*

2. ***GAD-2 to screen for anxiety****. Follow up with GAD-7 if indicated. Again, there are established cut-off scores that can be used to guide treatment selection.*

3. ***Caregiver Self-Assessment Questionnaire****. This asks questions specific to caregiver strain and related feelings. It helps the clinician understand just how stressed the caregiver is at the present time.*

4. ***More detailed information about assessment tools and methods can be found in:***

Gallagher-Thompson, D., Bilbrey, A. C., Qualls, S. H., Ghatak, R., Trivedi, R., & Waelde, L. C. (2023). *Family Caregiver Distress*. Hogrefe Publishing.

Interventions – Level 3: Psychoeducational Programs

- Develop adaptive cognitive and behavioral coping skills and promote caregiver self-efficacy by providing both information and opportunity to practice skills in and between meetings
- They are small, closed cohorts of 6–12 caregivers that meet weekly for 1–2 hours for a set number of weeks; can also be offered on- line over HIPAA-compliant zoom platform
- Effective psychoeducational interventions can be culturally adapted to meet unique needs of diverse communities

Evidence-Based Psychoeducational Programs for Caregivers:

- **Coping with Caregiving** developed & evaluated by Gallagher-Thompson et al. (2000, 2003).
- **Savvy Caregiving** developed by Hepburn et al. (2007). Online version: Hepburn et al. (2022)
- **Building Better Caregivers** developed & evaluated by Lorig and associates (2019).
- **iSupport** developed & evaluated by Baruah and associates (2021).
- **Caregiver: Thrive, Learn, & Connect** developed and evaluated by Montoro-Rodriguez et al. (2023)

*

History of CWC Psychoeducational Approaches

CWC

- Evidence-based: **used as an intervention in REACH**, translated & employed with diverse ethnic groups in one dozen RCTs; translational research as well with Latino and Chinese CGs
- Limitations: lengthy; insufficient focus on resilience / positive aspects of caregiving

OFJ

- **Condensed from 12 sessions to 8, 6, and 4**
- Piloted in several workshops with excellent results in terms of reducing CG depression
- Feedback: removed end of life planning segment & added content on positive aspects of caregiving

ACES

- **Developed new content on resilience, forgiveness, gratitude, and hope**: very well received by CGs!
- Woven throughout the course, including journaling activities to reinforce
- Piloted in February 2017, Fall 2017, Spring 2018 with some modifications to improve clarity; offered in community settings through the present time
- **Resulted in recent development of CAREGIVER TLC program**: Thrive, Learn, Connect – entirely on line workshop

Spanish

- **CAREGIVER TLC is now being culturally adapted for Latino caregivers** –funded by NIA; Principal Investigator: Julian Montoro Rodriguez, University of North Carolina at Charlotte

Core Elements of CWC for Family Caregivers

- There are **4 essential skills** taught in CWC: (Steffen et al., 2021).

1. behavioral activation -learning to plan positive activities into daily life

2. cognitive reframing – identifying and modifying negative thought patterns

3. identifying problem behaviors & their triggers & learning helpful responses

4. improving communication – with both person w/dementia & family members

* **Change (improved mental health) occurs via 2 mechanisms**:

  1. increased sense of self-efficacy / ability to manage difficult situations
  2. consistent skill practice to establish new behavioral habits

Interventions – Level 3 – Psychoeducational Caregiver TLC: Thrive, Learn, Connect

- 6 session workshop held over Zoom, 90 min each, closed group of 6-8
- access to a curated website with extensive resources available to them
  - Workshop session summary
  - Materials: Participant Guide, PDF of slide set, Handouts, Make Up Videos, Resources sort by session topic, Continuing Conversation videos
- ongoing monthly interactive 90 min meeting open to all who complete
  - 45 min webinar on topic
  - 45 min interactive discussion

Continuing Conversations Recordings

Please see below for recordings of these Webinars for those unable to attend the live sessions.

What are Challenging Behaviors?

- Anything that causes stress for both caregiver and person being cared for
- Common examples that most caregivers of persons living with dementia experience include: Wandering, repeating questions or comments, confusion and lack of ability to do things the care recipient used to be able to do, agitation, sleep disturbances, and overly assertive behavior
- Not "behaving badly" – there are many causes:

Learning about "Triggers", "Responses", and Ways to Modify Them

by Dolores Gallagher-Thompson, PhD, ABPP | Sept 15, 2021

Continuing Conversations

First meeting of the Continuing Conversation series.

Empowering Caregivers With a Voice: You Have a Voice... Use it!

by Lorrie Klemons, MSN, RN, CDP, EOLD | Jan 19, 2022

Continuing Conversations

Welcome to the World of Caregiver Empowerment.

Welcome

Welcome to companion webpage for participants of the Caregiver TLC program.

Here you will find information regarding what is expected of you as a participant in the Caregiver TLC research program. You will also find a list of the various manuals, articles, videos, and resources to help you explore the topics covered in the Caregiver TLC Workshop. In this workshop our focus is on you, the caregiver.

While the person you are caring for might benefit from the tools and skills that are taught in the workshop, our goal is to help you care for yourself so you in turn can care for someone else. Caregiver TLC Workshop consist of six weekly 90 minute sessions. The topics range from stress, mood, and anger management, to topics of building resilience, fitting in self-care, and finding ways to combat isolation.

Montoro-Rodriguez, Ramsey, Bilbrey, Kajiyama, Thompson & Gallagher-Thompson, 2023

Core Elements of Caregiver TLC for Family Caregivers

Session Components:

- Start with Deep Breathing, Check In, Agenda, Session Content, Take Away, Action Plan

Content Focus for Each of the 6 Sessions:

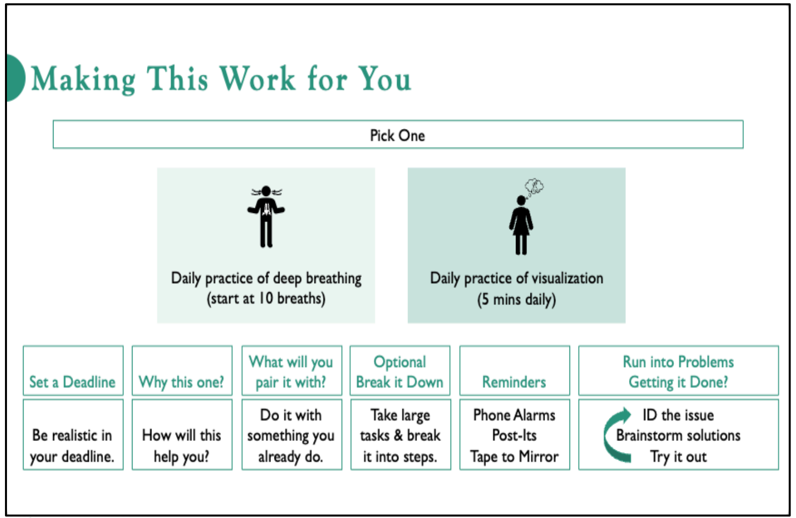
- Strategies for Stress Management
  - **Topic:** Stress **Skills:** Recognition of Stress Signs, Deep Breathing, Visualization
- Dealing with the Blues
  - **Topic:** Depressive Symptoms **Skills:** Behavioral Activation (Positive Activities)
- Bouncing Back
  - **Topic:** Resilience **Skills:** Balanced Worldview (finding the positive), Altas CareMap (care network)
- Filling the Well
  - **Topic:** Self-Care **Skills**: Finding small self care things to do, Sleep Hygiene, Cognitive Barriers
- Coping with Frustration
  - **Topic:** Anger **Skills:** Using Physical Signs and Thoughts to Identify Emotion, S.T.O.P Technique
- All by Myself
  - **Topic:** Social Connectedness & Workshop Review **Skills:** Various ways to stay connected via online means

Montoro-Rodriguez et al., 2023.

User-Friendly Materials and Use of Action Planning

Check In

- Done at the start of the next session
- Interactive discussion with heavy participant engagement
- Review barriers and successes
- Focus is on what was learned from experience – did the skill work? Were modifications needed?



Making This Work for You

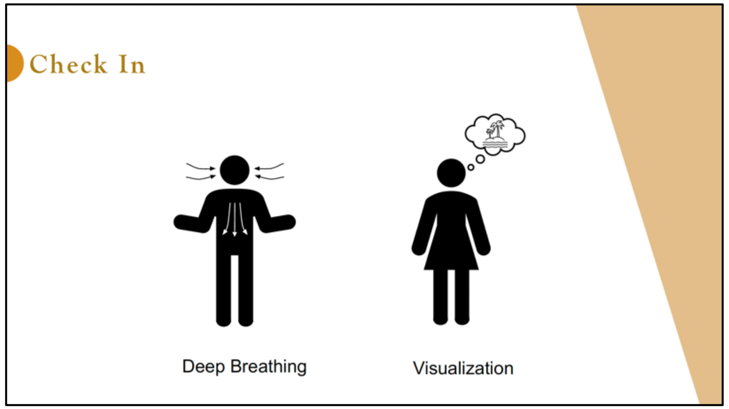
Pick One

Set a Deadline	Why this one?	What will you pair it with?	Optional Break it Down	Reminders	Run into Problems Getting it Done?
Be realistic in your deadline.	How will this help you?	Do it with something you already do.	Take large tasks & break it into steps.	Phone Alarms Post-Its Tape to Mirror	ID the issue Brainstorm solutions Try it out

Montoro-Rodriguez et al., 2023)

Action Plan

- Built using SMART Goals
- Aim is to teach the process of goal setting and overcoming barriers
- Participants are encouraged to write it down as the facilitator leads this discussion
- Participants are encouraged to share their goals, identify possible barriers and plans to deal it them



Check In

Interventions –Level 4- Psychotherapy

- Treatment of choice for caregivers experiencing significant distress –e.g., highly depressed
- Usually time limited -6–12 sessions focusing on caregiver-related distress
- For those with history of significant mental illness (e.g., bipolar disorder, unresolved PTSD), therapies focusing on caregiver issues should not replace whatever treatment is needed to meet other mental health needs

Examples of Psychotherapies that work with Caregivers:

- ***Cognitive behavioral therapy*** (CBT) and ***acceptance and commitment therapy*** (ACT) have the strongest evidence base and are most widely used in clinical practice with distressed caregivers
- ***Interpersonal therapy*** (IPT) is helpful when role transitions or complicated grief are present
- ***Psychodynamic therapy*** is helpful with caregivers dealing with current and anticipated losses, especially if they are in the early stages of the caregiving trajectory, trying to adapt to what's ahead
- ***Problem-solving therapy*** (PST) reduces stress by teaching a set of problem-solving skills
- ***Behavioral Activation***, a core component of CBT, is also effective (on its own) with depressed caregivers

Gallagher-Thompson, D., Bilbrey, A. C., Qualls, S. H., Ghatak, R., Trivedi, R., & Waelde, L. C. (2023). *Family Caregiver Distress*. Hogrefe Publishing.

Cognitive-Behavior Therapy (CBT)

- Present-oriented, problem-focused, encourages clients to try out new ways to deal with challenges- cognitive flexibility is key!
- Skill-building – clients learn new coping strategies – how to increase positive activities in their lives *and* how to question/modify unhelpful negative thoughts with more adaptive ones – e.g., “My life will never be the same since my spouse developed dementia” can become “It will be hard to adapt to life now but I’ve coped with big challenges before”
- Clients learn to become their own therapists –by completing behavioral assignments for “home practice” their sense of self-efficacy increases
- Maintenance plans help clients prepare for future negative events
- Highly effective with depressed adults, older adults, and CGs.

- (Laidlaw, Thompson & Gallagher-Thompson, 2018)

CBT As Used with Family Caregivers

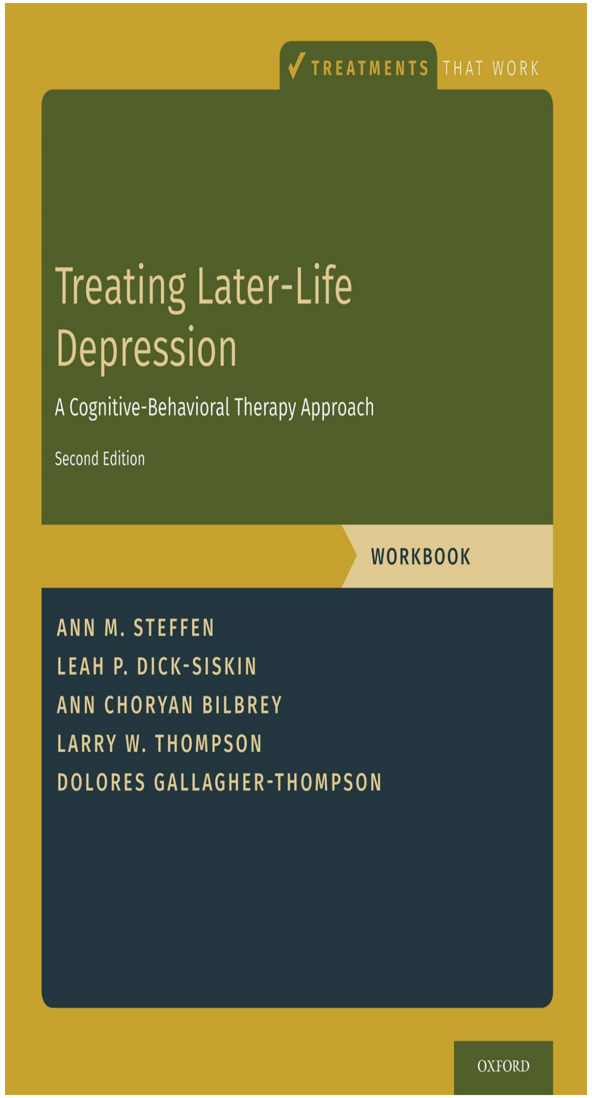
- Focus is on **identifying what aspects of caregiving are most related the depression** the caregiver is experiencing – e.g. they may be easily upset with their care recipient, say things they wish they hadn't, feel guilty and conclude they are "a bad caregiver" – This leads to overcompensation such as hypervigilance at night (causing sleep problems) for fear of their loved one wandering or doing other inappropriate things. This results in exhaustion and compromised ability to think clearly/make good decisions.
- Thoughts and self-evaluative judgments ("I'm a really bad caregiver") are addressed by teaching the skill of cognitive reframing; sleep hygiene helps with better quality sleep; problem solving about ways to reduce nighttime behaviors of the care recipient can be discussed and tried; and support with decision-making can be done through a skill such as "examining the evidence" for and against specific decisions.

Personalized Modules of *Treating Later-Life Depression – From Steffen, Thompson, and Gallagher-Thompson, 2022.*

Core Sections (for most patients)
Skills for Getting Started (Therapy Orientation and Goal Setting)
Skills for Feeling (Emotional Literacy, Cultivating Positive Emotions)
Skills for Doing (Behavioral Activation and Problem-Solving)
Skills for Thinking (Self-Compassion and Cognitive Reappraisal)

Personalized Sections (for some patients)
Skills for Brain Health (Preventing and managing cognitive concerns)
Skills for Managing Chronic Pain (Psychoeducation and Pain Management)
Skills for Healthy Sleep (Psychoeducation and Sleep Hygiene)
Skills for Caregiving (For family and informal caregivers)
Skills for Living with Loss (Support for healthy grieving)
Skills for Relating (Communication and interpersonal effectiveness skills)

Core Section
Skills for Wrapping Up (Termination processes and plans)



✓ TREATMENTS THAT WORK

Treating Later-Life Depression

A Cognitive-Behavioral Therapy Approach

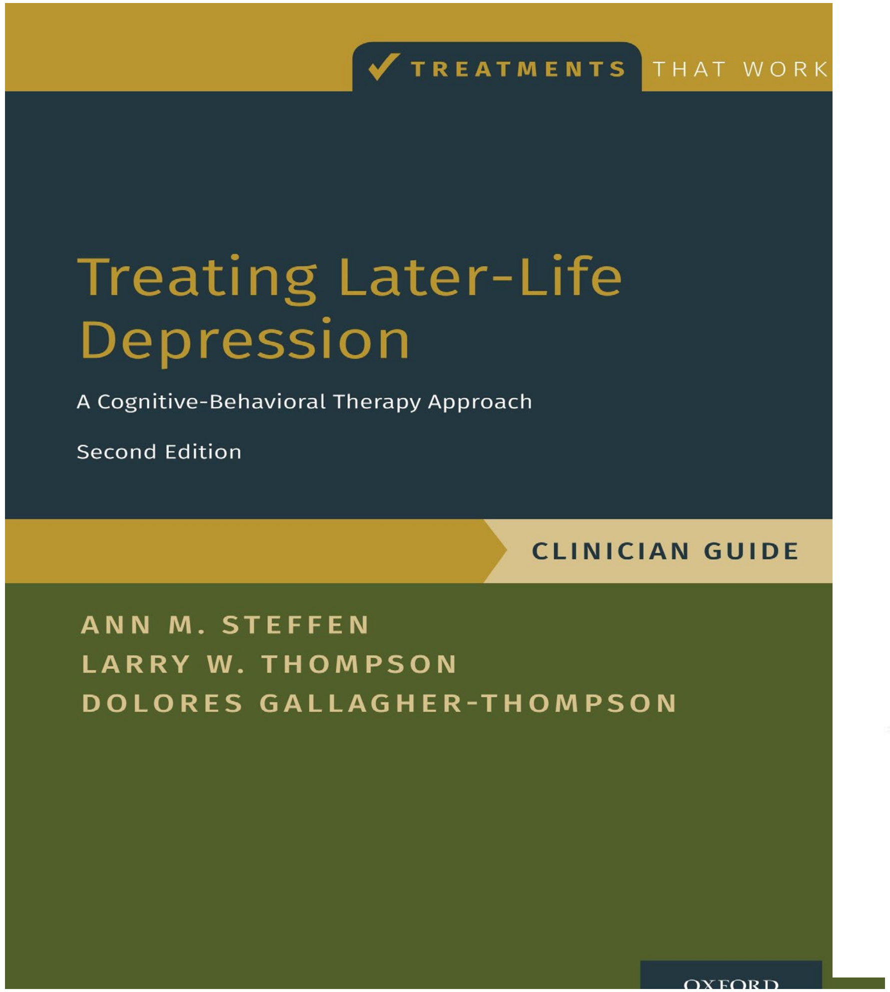
Second Edition

WORKBOOK

ANN M. STEFFEN
LEAH P. DICK-SISKIN
ANN CHORYAN BILBREY
LARRY W. THOMPSON
DOLORES GALLAGHER-THOMPSON

OXFORD

To Learn More…



TREATMENTS THAT WORK

Treating Later-Life Depression

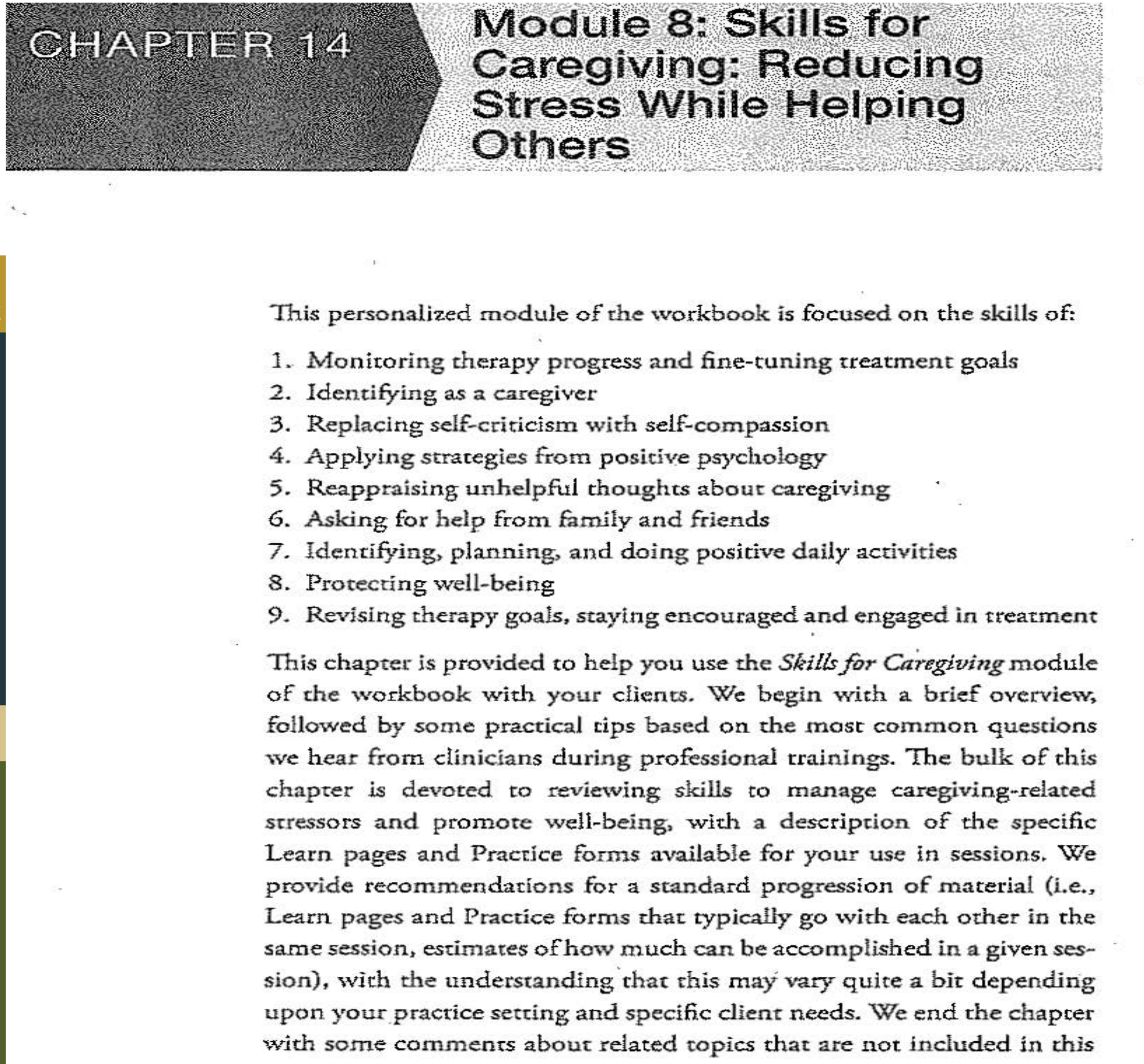
A Cognitive-Behavioral Therapy Approach

Second Edition

CLINICIAN GUIDE

ANN M. STEFFEN
LARRY W. THOMPSON
DOLORES GALLAGHER-THOMPSON

OXFORD



CHAPTER 14

Module 8: Skills for Caregiving: Reducing Stress While Helping Others

This personalized module of the workbook is focused on the skills of:

1. Monitoring therapy progress and fine-tuning treatment goals
2. Identifying as a caregiver
3. Replacing self-criticism with self-compassion
4. Applying strategies from positive psychology
5. Reappraising unhelpful thoughts about caregiving
6. Asking for help from family and friends
7. Identifying, planning, and doing positive daily activities
8. Protecting well-being
9. Revising therapy goals, staying encouraged and engaged in treatment

This chapter is provided to help you use the *Skills for Caregiving* module of the workbook with your clients. We begin with a brief overview, followed by some practical tips based on the most common questions we hear from clinicians during professional trainings. The bulk of this chapter is devoted to reviewing skills to manage caregiving-related stressors and promote well-being, with a description of the specific Learn pages and Practice forms available for your use in sessions. We provide recommendations for a standard progression of material (i.e., Learn pages and Practice forms that typically go with each other in the same session, estimates of how much can be accomplished in a given session), with the understanding that this may vary quite a bit depending upon your practice setting and specific client needs. We end the chapter with some comments about related topics that are not included in this

Skills for Caregiving to Learn and to Practice

Skills for Caregiving - Learn

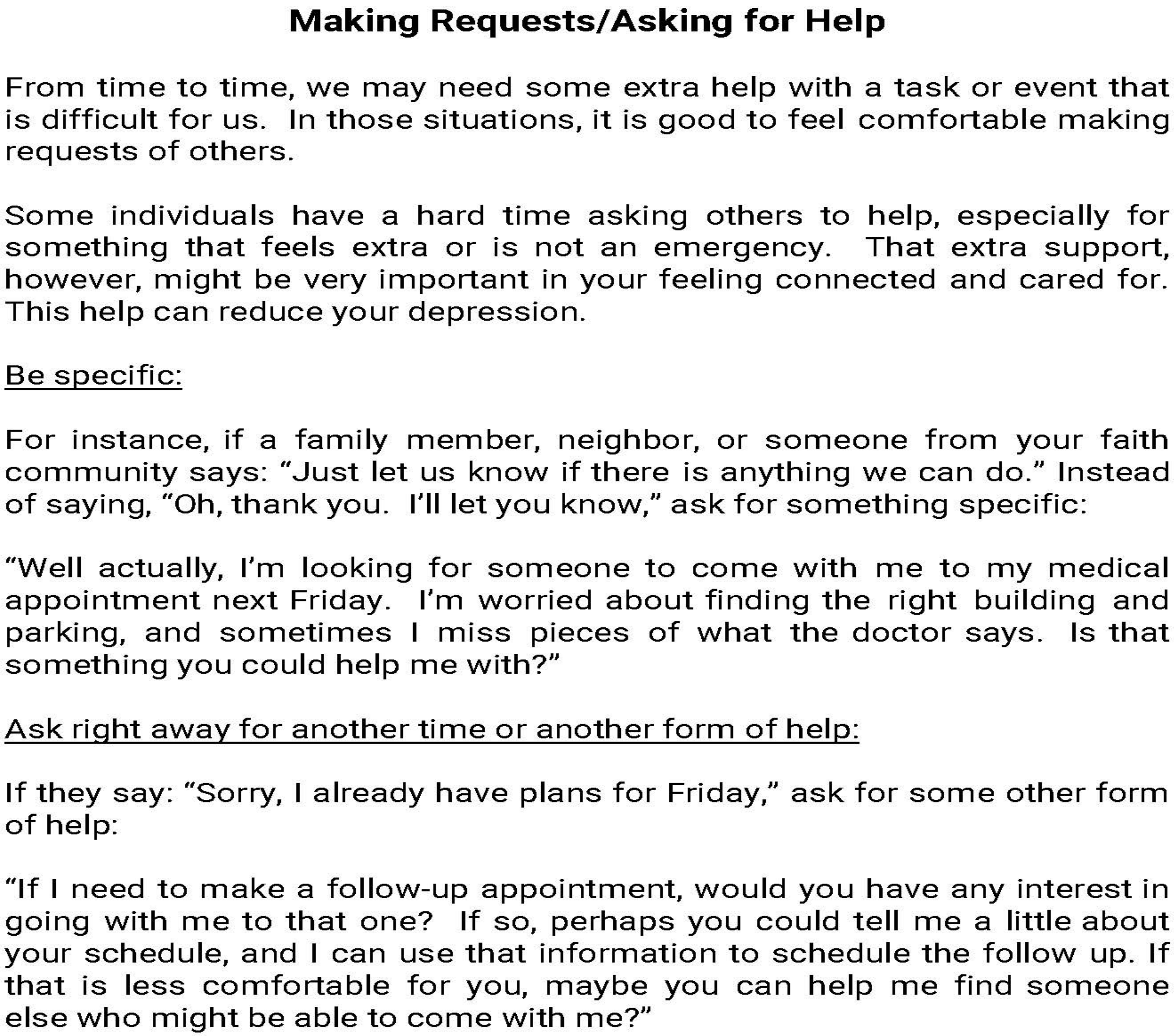
- Care 1 Learn Introduction to Skills for Caregiving
- Care 2 Learn Treat Yourself with Kindness, not Criticism
- Care 3 Learn **Self-Kindness for Caregivers**[T]
- Care 4 Learn Managing Caregiving Stress[T]
- Care 5 Learn Giving Yourself Credit as a Caregiver[T]
- Care 6 Learn **Encouraging Yourself**[T]
- Care 7 Learn Managing Your Unhelpful Thoughts[T]
- Care 8 Learn **Asking for Help from Friends and Family**[T]
- Care 9 Learn Positive Activities for Your Family Member[T]
- Care 10 Learn Increasing Your Daily Positive Activities
- Care 11 Learn **Planning Shared Positive Activities**[T]
- Care 12 **Learn** **Staying Able to Provide Care**[T]
- Care 13 Learn Your "R&R" (Rest and Recuperation)[T]
- Care 14 Learn National Resources for Caregivers in the U.S.[T]
- Care 15 Learn Setting Personal Goals Related to Caregiving[T]
- Care 16 Learn Ways to Think About Progress Toward Goals[T]

Skills for Caregiving - Practice

- Care 1 Practice Review of My Treatment Goals[T]
- Care 2 Practice Treating Myself Kindly in Caregiving Situations[T]
- Care 3 Practice **Managing "OK" Is Good Enough – My Examples**[T]
- Care 4 Practice Ways to Encourage Myself as a Caregiver[T]
- Care 5 Practice When It May Be Time to Step Back[T]
- Care 6 Practice **Revising Upsetting Thoughts About Caregiving**[T]
- Care 7 Practice Revising Unhelpful Thoughts About Caregiving
- Care 8 Practice **Asking for Help with Caregiving**[T]
- Care 9 Practice Positive Things for My Family Member to Do
- Care 10 Practice Rewarding Activities This Week for My Family Member[T]
- Care 11 Practice **My Rewarding Activities This Week**
- Care 12 Practice Our Shared Activities This Week[T]
- Care 13 **Practice** My Staying Able to Provide Care[T]
- Care 14 Practice My "R&R" (Rest and Recuperation)[T]
- Care 15 Practice My Goals for Managing Caregiving Stress[T]
- Care 16 Practice My Plan for Fully Participating
- Care 17 Practice My Review of Skills for Caregiving[T]

[T] *especially appropriate for telehealth*

Making Requests Asking for Help



Making Requests/Asking for Help

From time to time, we may need some extra help with a task or event that is difficult for us. In those situations, it is good to feel comfortable making requests of others.

Some individuals have a hard time asking others to help, especially for something that feels extra or is not an emergency. That extra support, however, might be very important in your feeling connected and cared for. This help can reduce your depression.

Be specific:

For instance, if a family member, neighbor, or someone from your faith community says: “Just let us know if there is anything we can do.” Instead of saying, “Oh, thank you. I’ll let you know,” ask for something specific:

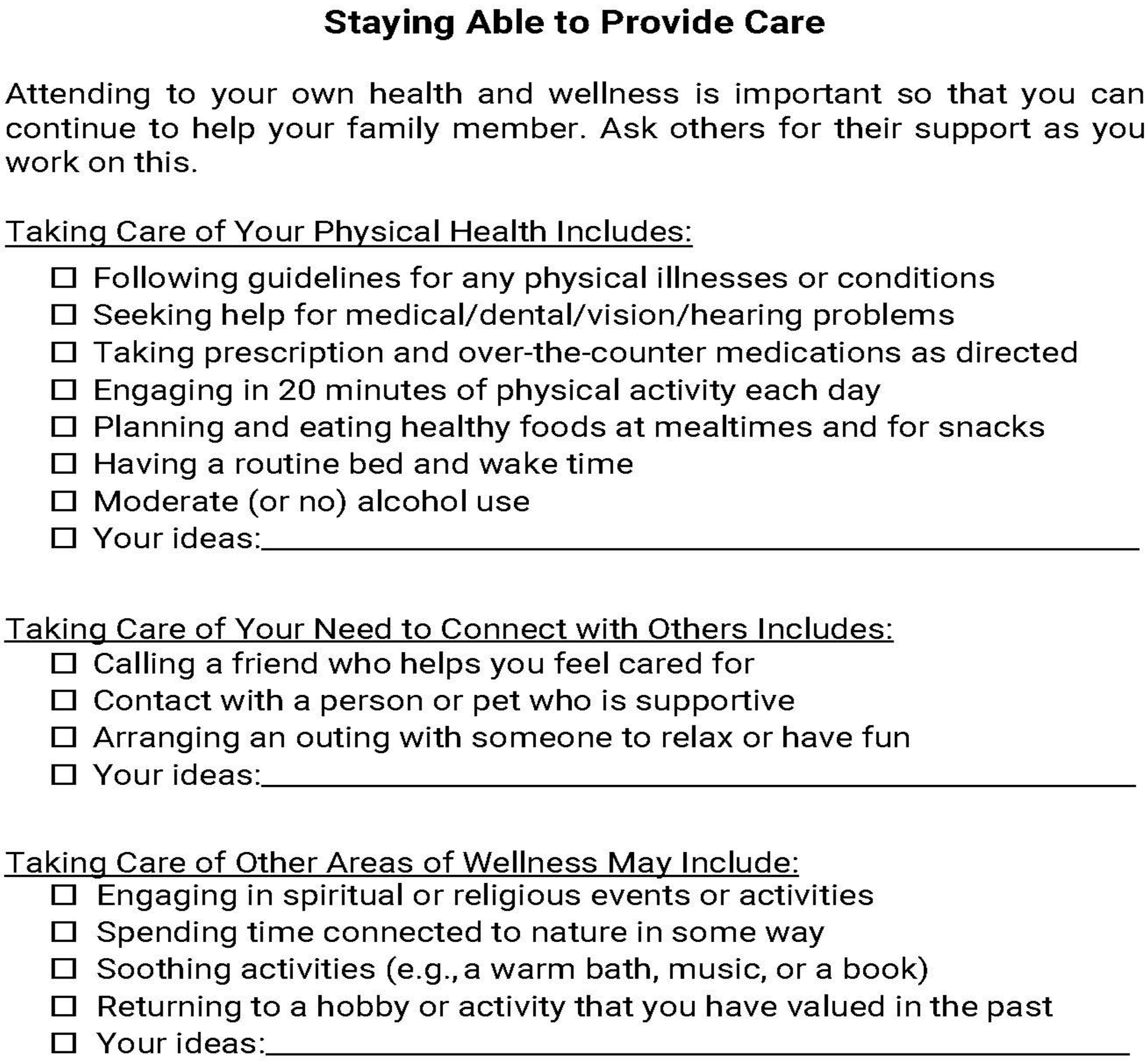
“Well actually, I’m looking for someone to come with me to my medical appointment next Friday. I’m worried about finding the right building and parking, and sometimes I miss pieces of what the doctor says. Is that something you could help me with?”

Ask right away for another time or another form of help:

If they say: “Sorry, I already have plans for Friday,” ask for some other form of help:

“If I need to make a follow-up appointment, would you have any interest in going with me to that one? If so, perhaps you could tell me a little about your schedule, and I can use that information to schedule the follow up. If that is less comfortable for you, maybe you can help me find someone else who might be able to come with me?”

Staying Able to Provide Care



Staying Able to Provide Care

Attending to your own health and wellness is important so that you can continue to help your family member. Ask others for their support as you work on this.

Taking Care of Your Physical Health Includes:

- ☐ Following guidelines for any physical illnesses or conditions
- ☐ Seeking help for medical/dental/vision/hearing problems
- ☐ Taking prescription and over-the-counter medications as directed
- ☐ Engaging in 20 minutes of physical activity each day
- ☐ Planning and eating healthy foods at mealtimes and for snacks
- ☐ Having a routine bed and wake time
- ☐ Moderate (or no) alcohol use
- ☐ Your ideas:________________________________

Taking Care of Your Need to Connect with Others Includes:

- ☐ Calling a friend who helps you feel cared for
- ☐ Contact with a person or pet who is supportive
- ☐ Arranging an outing with someone to relax or have fun
- ☐ Your ideas:________________________________

Taking Care of Other Areas of Wellness May Include:

- ☐ Engaging in spiritual or religious events or activities
- ☐ Spending time connected to nature in some way
- ☐ Soothing activities (e.g., a warm bath, music, or a book)
- ☐ Returning to a hobby or activity that you have valued in the past
- ☐ Your ideas:________________________________

Acceptance and Commitment Therapy (ACT)

- Focuses on learning how to accept and tolerate uncomfortable emotions – anger, anxiety, or sadness
- Encourages the person to “stay in the moment” and choose a meaningful course of action consistent with personal values
- Fosters **acceptance of problems** as an active coping strategy in itself – promoting the belief that many problems / challenges encountered in life cannot be “changed” or “controlled” but need to first be accepted for what they are
- (Márquez-González, Losada, & Romero-Moreno, 2014; Losada et al., 2015)

ACT as Used with Family Caregivers

- Caregivers of persons with dementia face many problems that can’t be “solved” or “controlled” and worsen as their CR declines
- By focusing in the “here and now” and learning techniques for mindfulness & self-acceptance, caregivers become more ‘centered’ and less emotionally driven
- This enables them to take a problem- solving stance to deal with problems that **CAN** be changed, or at least modified
  - Ex.: PWD will become less agitated if spoken to calmly and if loving touch/another form of nonverbal communication is used; this does not change the “problem” of difficult communication between CG & CR, but the situation is more manageable & less distressing to the CG

(Márquez-González, Losada, & Romero-Moreno, 2014; Losada et al., 2015)

TECHNOLOGY Can Augment Effects of Other Interventions:
a) Telephone-based Helplines

Institute on Aging California Friendship Line (800-971-0016)

- 24-hour toll-free Friendship Line
- Founded in 1973, it is the only accredited crisis line in the country for people aged 60 years and older, and adults living with disabilities

Alzheimer's Association 24/7 Helpline (800-272-3900)

- 24/7, 365 days a year
- Specialists and master's-level clinicians offer confidential support and information to people living with the disease, CGs, families and the public
- live chat from https://www.alz.org/help-support/resources/helpline available from 7a-7p(CST) M-F

Caregiver Help Desk (855-227-3640)

- Caregiving experts are available 8:00 AM – 7:00 PM ET.
- Hosted by Caregiver Action Network and staffed by caregiving experts, helps CGs to find the right information needed to help navigate complex caregiving challenges.
- Live chat/email available from https://caregiveraction.org/

b) ONLINE SUPPORT GROUPS

Family Caregiver Alliance offers an unmoderated email list style support for families, partners, and other CGs who want a safe place to discuss the stresses, challenges, and rewards of providing care for adults with chronic debilitating health conditions.
https://www.caregiver.org/connecting-caregivers/support-groups/

Well Spouse Association org for spousal CGs across all chronic illnesses. Although the groups are member-based, the website has many free resources https://wellspouse.org/

Check out the major organizations for the illness of the person you are caring for such as:

Michael J Fox Foundation

- for Parkinson Disease has a support group page that lists available online groups. https://www.michaeljfox.org/news/support-groups

Alzheimer's Association

- offers a searchable database of support groups, supports research, and offers great information via website https://www.alz.org/events/event_search

Lewy Body Dementia Association

- LBDA raises awareness, supports patients, families and CGs and promotes scientific advancements. They offer a support-group-locator tool to help you find local group. https://www.lbda.org/local-support-groups/

Find your local **Area on Aging** https://www.n4a.org/

c) ONLINE MESSAGE BOARDS

AARP Online Community (AARP) https://community.aarp.org

- For all CGs
- Don’t have to be an AARP member or be over the age of 50 to use
- They offer a variety of forums including a set specifically for CGs with CG tips, knowledge base articles, chat, plus more

ALZ Connected (Alzheimer’s Association) https://www.alzconnected.org/

- free online community
- Alzheimer’s and other Dementias
- People with the disease, CGs, Family members, Friends, Individuals who have lost someone to Alzheimer’s

Smart Patients (Family Caregiving Alliance / Smart Patients)
https://www.smartpatients.com/partners/fca

- For CGs of adults with chronic physical or cognitive conditions such as Alzheimer’s, stroke, Parkinson’s, and other illnesses

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d) FACEBOOK PRIVATE GROUPS

Memory People https://www.facebook.com/groups/180666768616259
They bring real-time Support to patients, CGs, advocates, family members and professionals who are dealing with Alzheimer's/dementia or any memory impairment.

The Purple Sherpa Basecamp: Dementia Family Caregiver Support Group
This is a place to share what we've learned as care-partners, to vent and support one another, and to break the silence that leaves so many CGs feeling alone.
https://www.facebook.com/groups/ThePurpleSherpaBasecamp/

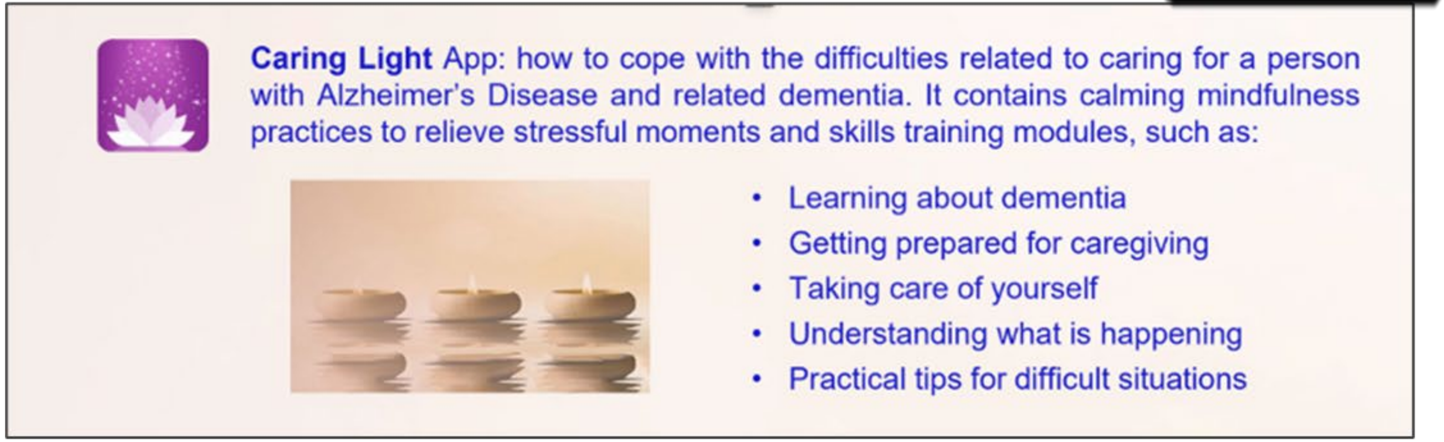
Working Daughter
This is for women who are balancing caring for an aging parent with their career. They promote community, support, and encouragement. They encourage you to share questions and advice.
https://www.facebook.com/groups/workingdaughter/

e) Smart Phone APPS

Download on the App Store

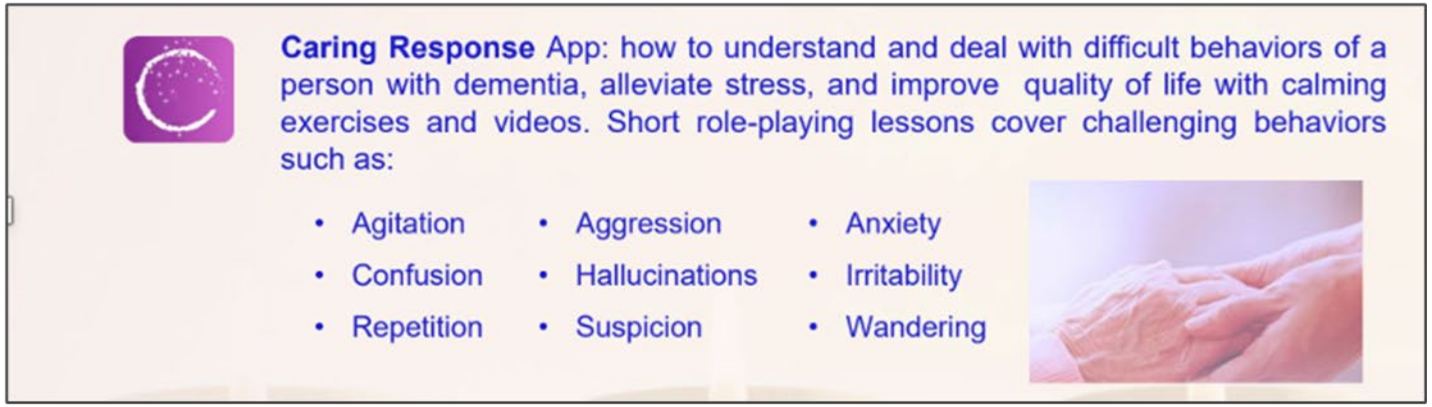
GET IT ON Google Play

Website photozig.com/app



Caring Light App: how to cope with the difficulties related to caring for a person with Alzheimer's Disease and related dementia. It contains calming mindfulness practices to relieve stressful moments and skills training modules, such as:

- Learning about dementia
- Getting prepared for caregiving
- Taking care of yourself
- Understanding what is happening
- Practical tips for difficult situations



Caring Response App: how to understand and deal with difficult behaviors of a person with dementia, alleviate stress, and improve quality of life with calming exercises and videos. Short role-playing lessons cover challenging behaviors such as:

- Agitation
- Confusion
- Repetition
- Aggression
- Hallucinations
- Suspicion
- Anxiety
- Irritability
- Wandering

Caring Mind App: mindfulness and cognitive behavioral therapies for reducing anxiety and stress related to caregiving. The app is under development, and we are looking for participants in our research project. If you are interested, please contact us at info@photozig.com

(Download at photozig.com/apps)

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Trajectory of Caregiving

(Adapted from Gallagher Thompson et al., 2020)

Caregiver and Care Recipient's Culture Sets the Context for the Caregiving Trajectory

	Early Stage	Transition	Middle Stage	Transition	Late Stage
Care Recipient	▪ CR diagnosis ▪ Outpatient Care ▪ Wellness Focus ▪ Slowing down decline ▪ Stabilization	▪ Increased interaction between CR & HCS	▪ Escalation of: Medical care Behavioral issues Dependence on CG	▪ Increased interaction between CR & HCS	▪ Total dependence on CG ▪ Possible move to LTC ▪ Palliative/ EOL Care
Caregiver	▪ Conscious adoption of role ▪ Denial, grief, conflict ▪ Information seeking ▪ HCS interface ▪ CR advocacy ▪ Care planning ▪ Family planning	▪ Increased dependency resulting in adjustments to social & work life	▪ Increased responsibility for all decision making ▪ Changes in CG mental & physical health ▪ CR/CG relationship changes ▪ Anticipatory grief	▪ Higher burden & strain affecting mental & physical health	▪ Decision to remain in home or move to LTC ▪ Anticipatory grief ▪ Bereavement, sadness, relief ▪ Adjustment to life after caregiving
Health System Interventions	▪ CR assessment, diagnosis ▪ CG strengths & vulnerabilities assessment ▪ Education/coping skills	▪ Increased utilization of HCS	▪ Medical care for co-morbidities ▪ Training for at-home nursing tasks ▪ Continued care planning ▪ Case management	▪ Increased utilization of HCS	▪ Support for EOL care ▪ Balancing selfcare & care tasks ▪ Support groups

Culture includes both their Heritage and the Health Systems Culture they interact with

The Trajectory of Caregiving: Different Interventions at Different Stages

- <u>How caregivers experience distress varies</u> by cultural background, earlier life experiences, types of tasks to be done, degree of available support, resilience, coping strategies, financial security, AND - length of time in the role: some “burn out” quickly -others “stay the course”
- <u>What will benefit them varies</u> according to their mental health needs, their receptivity to engage in effective programming, and the current demands of their caregiving situation. Clearly “one size does not fit all.” Caregivers have different levels of interest to receive education/ support / skill training/ psychotherapy
- <u>For most, caregiving is a “family affair”</u> –including the families we are born into and those we choose. Can we develop forms of therapy that engage the family unit? Would that be more helpful at certain points along the trajectory?

- We need <u>new longitudinal research</u> to address the question of which interventions are most appropriate at which points in the trajectory of care. This requires adequate funding to be successful. Recent “caregiving summits” recommend this s does the <u>NAC Spotlight on Caregiver Mental Health</u> (Oct. 2023)

NAC Spotlight on Mental Health: Supporting the Mental Health of Family Caregivers

- **Behavioral health equity** – support mental health coverage for all caregivers regardless of race/ethnicity, socioeconomic status, sexual orientation, language or geographic location
- **Mental health parity** – expand mental health coverage for family caregivers through such avenues as Medicare Advantage; Medicare Part D; Medicaid; and private health insurances
- **Mental health professional workforce readiness and shortages** – reimburse providers at levels that will incentivize them & support programs to encourage expansion of the workforce including community health workers
- **Adoption of "Whole Health System" models** that are person-and family-centered & focus on treatment of mind and body – e.g., co-location of mental health services in primary care; use of a team approach to assess and treat caregivers (as well as the persons they care for).

(National Alliance of Caregivers, 2023)

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WHAT ARE THE MAIN GAPS IN MENTAL HEALTH CARE FOR CAREGIVERS?

Although Barbara McLendon, Alzheimer’s Los Angeles will be covering Gaps more in-depth I wanted to touch on these three:

- First, recognition that Caregivers’ ***mental health matters***!
- Second, we need culturally relevant and linguistically appropriate interventions for diverse caregivers.
- Third, increased funding for research and demonstration projects focusing on unique needs and intervention approaches for specific groups is essential so that programs are developed that meet caregivers’ changing mental health needs over time, as they progress through the trajectory of dementia care.

THANK YOU!

If you have any questions please reach out!

Dolores Gallagher-Thompson, PhD
dolorest@stanford.edu

You can get more information on training opportunities we provide to clinicians who want to learn to deliver evidence-based programs discussed today on our website:

www.optimalagingcenter.com

Gaps and Future Directions

Barbra McLendon, Policy Director, Alzheimer's Los Angeles

Committee Questions and Discussion

Public Comment

- **In-Person Comments:** Raise your hand to enter the line to make a public comment or ask a question.
- **Verbal Comments:** You can “raise your hand” in the Reactions feature of Zoom or press *9 on your phone dial pad to enter the line for a verbal comment or question. The moderator will unmute your line.
- **Written Comments:** You may submit comments and questions throughout the meeting using the **Zoom Q&A.**

Break

The meeting will resume at 12:35 p.m.

California Department of AGING

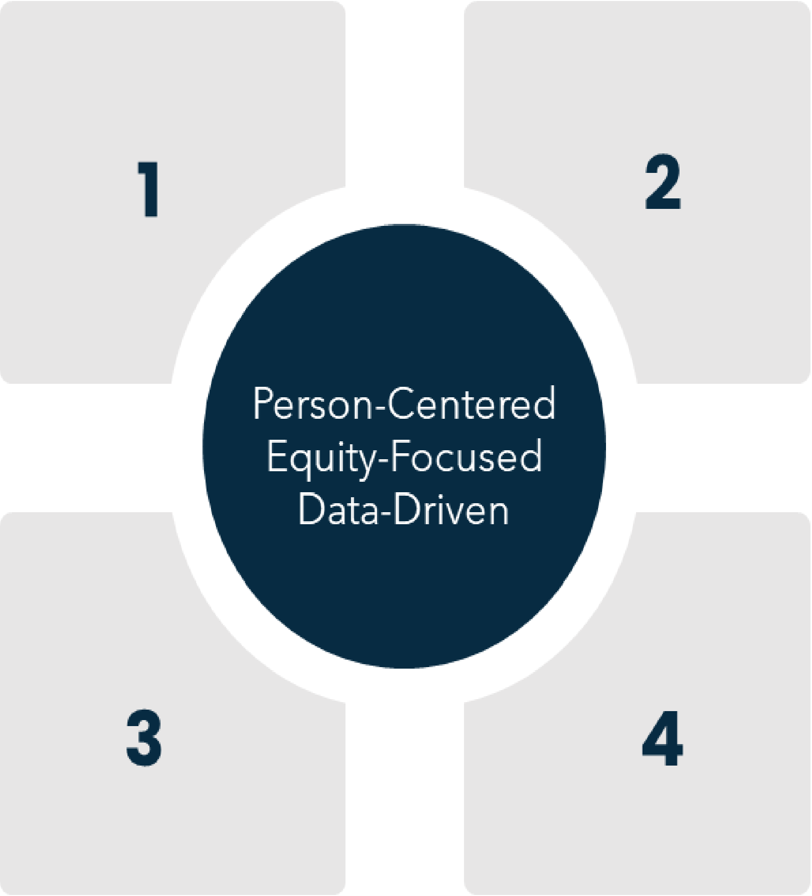
Master Plan for Aging
Goal #4: Caregiving that Works

Susan DeMarois, Director

7 Current CDA-led Caregiving Initiatives

1. Supporting our Infrastructure: Area Agencies on Aging (AAAs) and Caregiver Resource Centers (CRCs)
2. CalGrows and related workforce investments (IHSS/CHWs)
3. Federal ACL Grant: CAlz Connect
4. HCBS Gap Analysis
5. LTSS Financing
6. Caregiver Equity Roadmap
7. Bridge to Recovery & Cal-COMPASS

California Department of Aging “Core Four”



No Wrong Door System

MPA Initiative 72

CA2030 Initiative

MPA Initiative 74

Aging & Disability Resource Connection Sustainability

MPA Initiative 71

CDA Data Strategy

MPA Initiative 70

Key Initiatives: CA 2030

CA2030 has engaged more than 270 local, state and federal expert perspectives to inform work on six key areas integral to the AAA network:

1. Governance
2. Geography & demographics
3. Core programs & services
4. Key performance measures
5. Funding sources & capacities
6. Branding, communications & outreach

Visit CA2030 Website: www.aging.ca.gov/CA2030

CALIFORNIA HEALTHY BRAIN INITIATIVE AND BOLD UPDATE

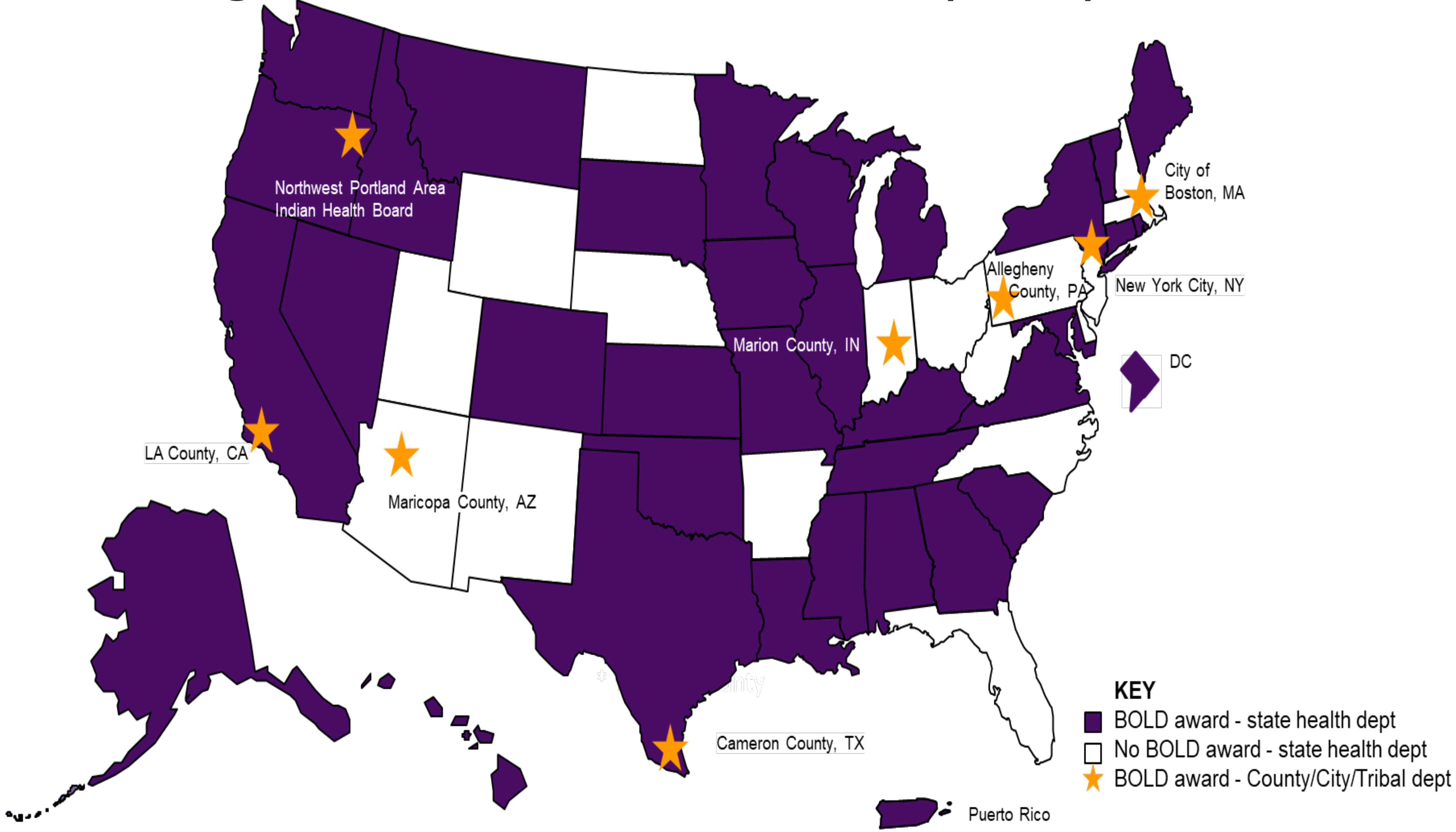
LYNNLEY STERN

ALZHEIMER'S DISEASE PROGRAM

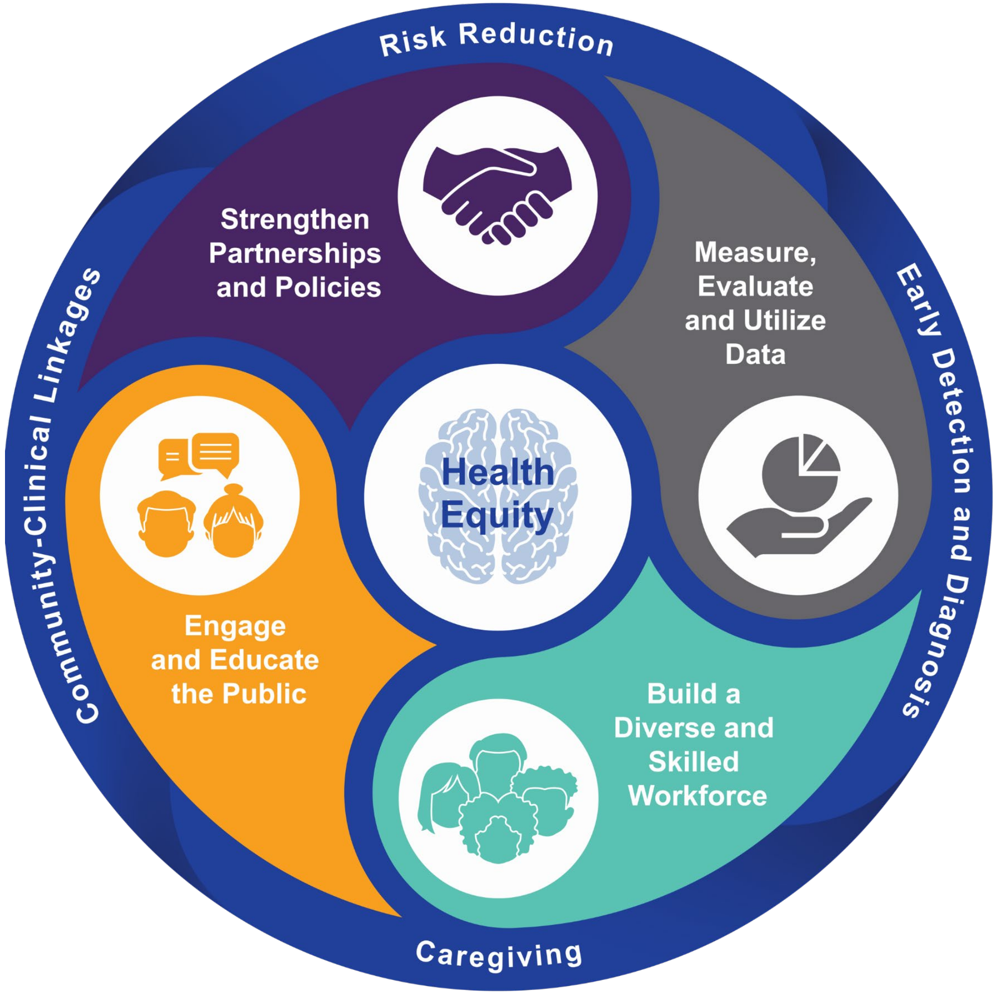
CHRONIC DISEASE CONTROL BRANCH

CALIFORNIA DEPARTMENT OF PUBLIC HEALTH

BOLD Program Awards — 2023-2028 (n=43)



CDC Conceptual Framework for the Healthy Brain Initiative Road Map



Healthy Brain Initiative: State and Local Road Map for Public Health, 2023-2027 (cdc.gov)

Purpose:

- Advance cognitive health as an integral component of public health
- Implement the CDC Healthy Brain Initiative 2023-2027 Road Map

Four Traditional Domains of Public Health:

- Engage and Educate
- Strengthen Partnerships and Policies
- Build a Diverse and Skilled Workforce
- Measure, Evaluate, and Utilize Data

CALIFORNIA HEALTHY BRAIN INITIATIVE

- Initiative Purpose and Goal
- Phase 1: 20/21-21/22 Pilot Project
- Phase 2: 22/23 Increased Funding

★ Non-Competitive Pilot Renewal Contracts (6)

★ Competitive RFA Grants (6+)

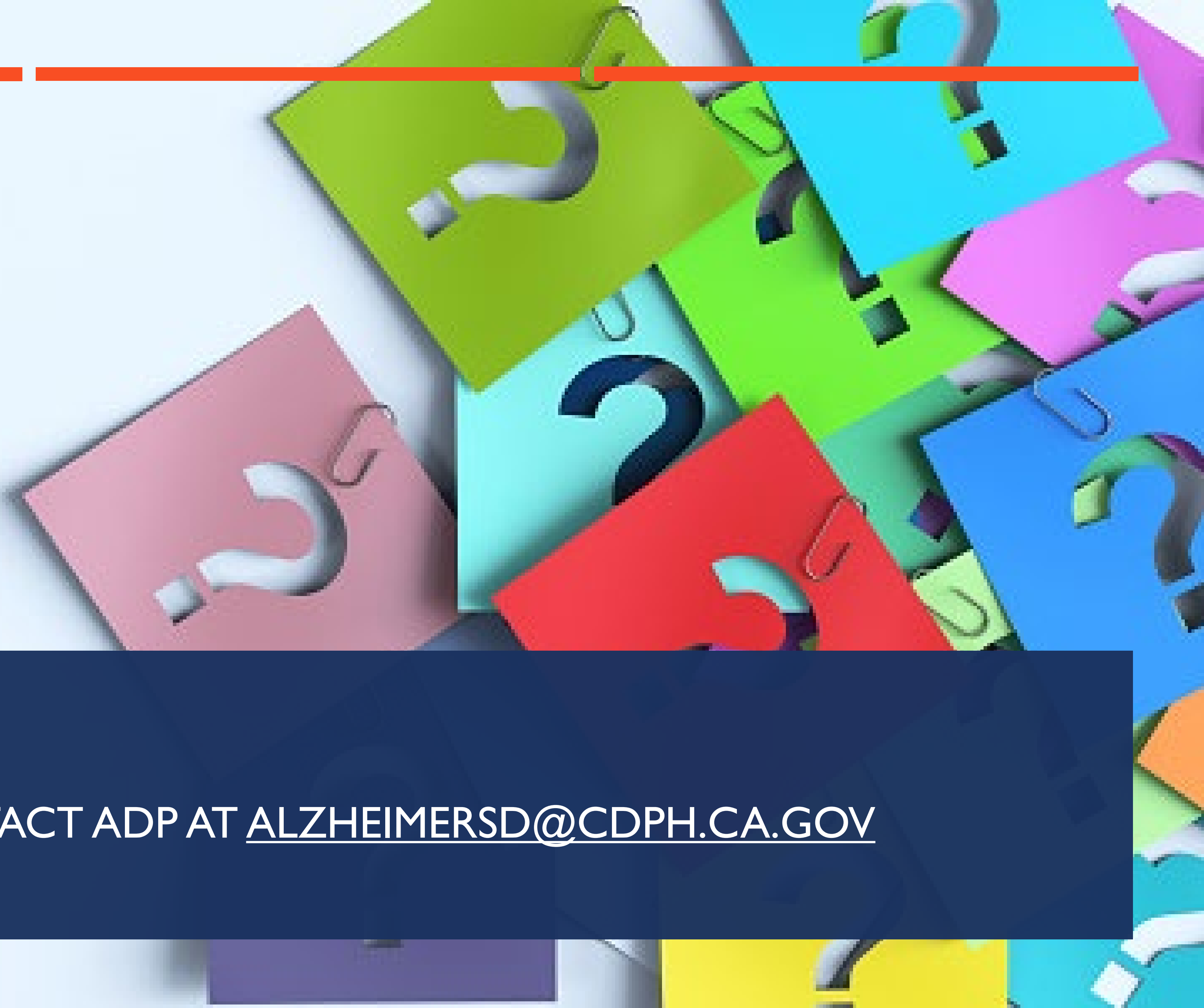
- 23/24 BOLD Funding
  - $400k annually from 9/30/23 to 9/29/28
  - Support and continue the HBI work

Thirteen HBI Counties

Alameda
Butte
Los Angeles
Monterey
Orange
Placer
Sacramento
San Diego
San Luis Obispo
Santa Clara
Shasta
Siskiyou
Sutter

BOLD REQUIREMENTS

- Attend the quarterly Alzheimer's Advisory Committee Meetings
- Present quarterly to the Alzheimer's Advisory on our statewide and local efforts to advance the CA HBI work
- Facilitate partnership building with other statewide partners within the Alzheimer's Advisory Committee including the California Department of Aging, Department of Health Care Services, California Alzheimer's Disease Centers (CADCs), and clinical experts at academic institutions conducting Alzheimer's disease and related dementias research



THANK YOU

FOR QUESTIONS, CONTACT ADP AT ALZHEIMERSD@CDPH.CA.GOV

Priorities from August Presentation

Darrick Lam

Committee Vice Chair

Vice President, Self-Help for the Elderly

Wynnelena Canlas Canio, MD

Chief of Geriatric Medicine, Kaiser Permanente Rafael, Committee Member

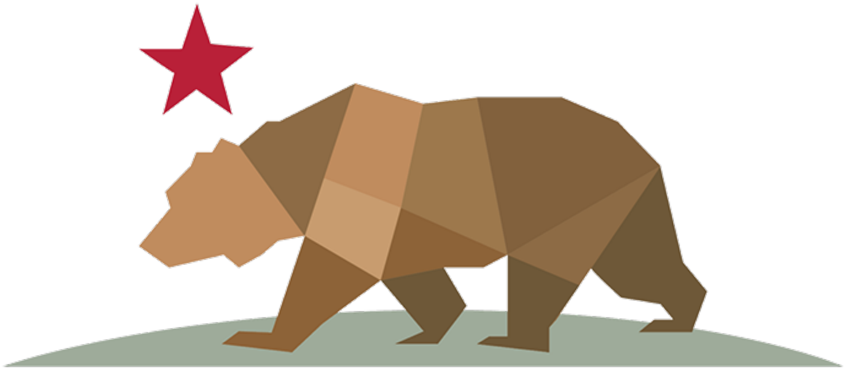
Alzheimer's
LOS ANGELES

State Legislative Update

Barbra McLendon, Public Policy Director

Legislative Update

Caregiver Bills



- AB 518 – **Paid Family Leave**
  - Would expand eligibility for benefits under the paid family leave program to include individuals who take time off work to care for a seriously ill individual related by blood or whose association with the employee is the equivalent of a family relationship.
  - Held at request of Sen. Durazo- Now a two-year bill

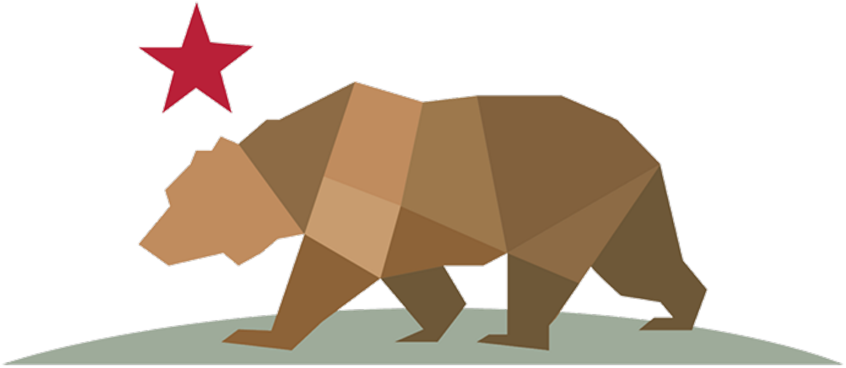
Legislative Update

Caregiver Bills Vetoed by Governor

- AB 524 – **Family Caregiver Status**
  - Would prohibit employment discrimination on account of family caregiver status, as defined, and would recognize the opportunity to seek, obtain, and hold employment without discrimination because of family caregiver status as a civil right.
- AB 575- **Paid Family Leave- Use of Vacation Time**
  - Would no longer require caregivers to use vacation time before accessing paid family leave benefits. Also deletes the restriction that an individual is not eligible for PFL benefits if another family member is ready, willing, and able and available for the same period of time in a day to provide the required care.

Legislative Update

Signed by Governor



- SB 616 **– Sick Leave Accrual**
  - Expands sick leave accrual from 3 days to 5

- AB 48 – **Nursing Home Resident Rights-** Adds to patient bill of rights the right to receive information on psychotherapeutic drugs in order consent or refuse drugs

- SB 525- **Healthcare Worker Minimum Wage -**enacts a phased in multi-tiered statewide minimum wage schedule for health care workers employed by covered healthcare facilities

Alzheimer's Los Angeles

Alzheimer's
LOS ANGELES

844.HELP.ALZ
AlzheimersLA.org

@AlzheimersLA #AlzheimersLA

2023 Legislative Update

November 2, 2023

Eric Dowdy
Vice President, Public Policy

ALZHEIMER'S ASSOCIATION®

Mission

The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

Vision

A world without Alzheimer's and all other dementia®.

AB 21 (Gipson) – Law Enforcement Training 2-YEAR

- Dementia competency included in crisis intervention training for police training officers
- Alzheimer's and dementia specific training required for all officers by 2030
- Next steps: Working with Peace Officer Standards and Training (POST) on updating curriculum

AB 387 (Aguiar-Curry) Alzheimer’s Advisory Committee 2-YEAR

- Renames committee to: “Alzheimer’s Disease and Related Conditions Advisory Committee”
- Expands committee from 14 to 21 (max 25)
- Removes stigmatizing language such as “suffering from” to “living with”
- Removes term limits for members living with dementia

- Adds:
  - Local Health Jurisdictions
  - First Responders
  - Consumer Org (1)
  - CA Commission on Aging
  - Primary Care Physicians
  - 2 ex officio, non-voting members (Senator & Assemblymember)
  - 4 CHSS Secretary Members

SB 639 (Limón) Alzheimer’s Diagnostic Hubs 2-YEAR

- Focuses the California Alzheimer’s Disease Centers (CADCs) on diagnostic work
- CADCs are currently required to provide the following:
  - Direct diagnostic services
  - Research
  - Training to individuals and families impacted by Alzheimer’s
  - Training to health professionals
- Moves Dementia Care Aware into the CADS
- Exploring funding

- Adds:
  - Local Health Jurisdictions
  - First Responders
  - Consumer Org (1)
  - CA Commission on Aging
  - Primary Care Physicians
  - 2 ex officio, non-voting members (Senator & Assemblymember)
  - 4 CHSS Secretary Members

Additional Bills of Note

- AB 385 (Ta) – Implements an Alzheimer’s Public Awareness Campaign 2-YEAR
- AB 423 (Maienschein) Wondering Task Force at DOJ 2-YEAR
- AB 786 (Bains) Restraining Orders: Filing Fees GUT & AMEND
- AB 820 (Reyes) State Boards & Commissions: Seniors 2-YEAR
- AB 1313 (Ortega) CDA Case Management Pilot Program 2-YEAR
- AB 1387 (Ting) RFP to promote immigrants to become IHSS providers 2-YEAR
- AB 1672 (Haney) Allow IHSS providers and employers to negotiate their contracts at the state level rather than the county 2-YEAR
- SB 37 (Caballero) Housing subsidy 2-YEAR
- SB 357 (Portantino) Vehicles: Physician & Surgeon Reporting 2-YEAR
- SB 544 (Laird) Bagley-Keene Open Meeting Act CHAPTERED

Questions?

Eric Dowdy, MPPA
VP, Public Policy
eedowdy@alz.org

Finalization of Recs. & Items for CalHSS Secretary

Darrick Lam

Committee Vice Chair

Family Member Representative

Public Comment

- Time is reserved on the meeting agenda for public comment.
- **In-Person Comments:** Raise your hand to enter the line to make a public comment or ask a question.
- **Verbal Comments:** You can "raise your hand" in the Reactions feature of Zoom or press *9 on your phone dial pad to enter the line for a verbal comment or question. The moderator will unmute your line.
- **Written Comments:** You may submit comments and questions throughout the meeting using the **Zoom Q&A.**

Closing Comments and Next Steps

Darrick Lam

Committee Vice Chair

Family Member Representative

2024 Meeting Schedule

- **February 1**
- **May 9* (moved to 2nd Thursday)**
- **August 1**
- October 8 – CA for All Ages & Abilities (MPA)
- **November 7**

Meetings held in-person in Sacramento with Zoom option

Thank You!

Visit the [CalHHS Alzheimer's Disease & Related Disorders Advisory Committee webpage] for:

- More information about the Committee
- Upcoming meeting dates
- Presentations, recordings, and transcripts of past meetings