How to Support and Empower Caregivers of People Living with Dementia

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National Seminar 2025

September 15-17, 2025 • Philadelphia, PA

capc.org/seminar

Learning Objectives

Following this webinar, participants will be able to:

1. Describe the value of addressing and including caregivers in patient care
2. Implement strategies to better integrate and empower caregivers during the clinical encounter
3. Improve operational capacity to support patients and caregivers through workflow and billing changes
4. Identify meaningful community resources for clinicians to better support caregivers where they are

Who's Here?

- Primary care provider
- Palliative care provider
- Care partner
- Other (drop in chat)

What is Palliative Care?

Palliative care (pronounced pal-lee-uh-tive) is specialized medical care for people living with a serious illness. It focuses on relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

- Palliative care is provided by a specially-trained team of doctors, nurses, social workers, chaplains, and other specialists who work together with a patient's other doctors to provide an extra layer of support.
- Based on need, not prognosis, it is appropriate at any age and at any stage in the illness, and it can be provided along with curative treatment.

Dementia and Palliative Care

- Palliative care is “person-centered” care
  - Recognize patients’ health problems as *they* see them
  - Focus on the whole person
  - **Include caregivers in the unit of care**
  - Provide a foundation for better recognition of health problems and needs over time
  - Facilitate appropriate care for these needs in the context of other needs

How to Support and Empower Caregivers of People Living with Dementia

ALZHEIMER'S ASSOCIATION

In honor of…

- ❑ Buy groceries/ prepare meals
- ❑ Pick up/ manage medications
- ❑ Transportation
- ❑ Emotional support
- ❑ Fix items/ maintain the home
- ❑ Manage bills/ expenses
- ❑ Help eat/ dress/ bathing/ toileting

CAREGIVING in the U.S. 2020

The number of Americans providing unpaid care has increased over the last five years.*

43.5 million (2015) → 53 million (2020)

18% (2015) → 21% (2020)

NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.**

More Americans are caring for more than one person.

18% (2015) → 24% (2020)

More family caregivers have difficulty coordinating care.

19% (2015) → 26% (2020)

More Americans caring for someone with Alzheimer's disease or dementia.

22% (2015) → 26% (2020)

More family caregivers report their own health is fair to poor.

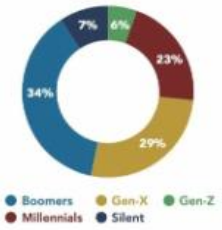
17% (2015) → 21% (2020)

23% OF AMERICANS SAY CAREGIVING HAS MADE THEIR HEALTH WORSE.

Who are today's family caregivers?

39% MEN

61% WOMEN



45% HAVE HAD AT LEAST ONE FINANCIAL IMPACT

61% WORK

AARP Family Caregiving™

*Provided care to an adult or child with special needs.
**The remainder of this data is based on the 19% or 48 million caregivers caring for an adult.

URL: www.aarp.org/uscaregiving DOI: https://doi.org/10.26419/ppi.00103.002

Caregiving in the U.S. 2020,
National Alliance for Caregiving and AARP
For media inquiries, contact Media@aarp.org

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Caregivers Are Key

70% of people living with dementia reside in the community/
50% of ALF and nursing home residents have dementia/ cognitive impairment

- Enable loved ones to remain in their own home/ communities for longer
- Manage behavioral disturbances (wandering)
- Attend to physical needs

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.

2024 Alzheimer's Disease Facts & Figures

NEARLY
7 MILLION
AMERICANS ARE LIVING WITH ALZHEIMER'S

THE LIFETIME RISK FOR ALZHEIMER'S AT AGE 45 IS

1 in 5 FOR WOMEN

1 in 10 FOR MEN

Older Black Americans are
2X AS LIKELY
to have Alzheimer's or other dementia than Whites.

BETWEEN 2000 AND 2021, DEATHS FROM HEART DISEASE HAVE
DECREASED 2.1%

WHILE DEATHS FROM ALZHEIMER'S DISEASE HAVE
INCREASED 141%

1 IN 3
SENIORS DIES WITH ALZHEIMER'S OR ANOTHER DEMENTIA

IT KILLS MORE THAN
BREAST CANCER AND **PROSTATE CANCER**
+
COMBINED

Older Hispanic Americans are
1.5X AS LIKELY
to have Alzheimer's or other dementia than Whites.

ALZHEIMER'S ASSOCIATION®

Community-Level Resources

24/7

Helpline
800-272-3900

Always answered live by trained staff

- Masters level clinicians available
- Language line offers 150 languages and dialects
- Gateway to our Programs & Services
- Available for clinicians

>100

Support Groups

Live and Virtual Support Groups led by trained volunteers

- Audience-specific: (ie. early stage, late stage, under 40 caregivers, LGBTQ caregivers, younger onset, etc.)
- Available in-person and virtually to meet the needs of caregivers

>50

Education programs per month

Delivered by our staff and trained volunteers. Available virtually and in person

- Know the 10 Signs
- Healthy Living for Brain and Body
- Understanding Dementia Behaviors
- Empowered Caregiver Series
- Managing Money

Who Are the Dementia Caregivers?

- **Two-thirds** of caregivers are women, and **one-third** are daughters.
- **About one in three** caregivers is age 65 or older.
- **One quarter** of dementia caregivers are “sandwich generation” caregivers, taking care of both an aging parent and child.
- **41%** of caregivers have a household income of $50,000 or less.
- **66%** live with the care recipient in the community.

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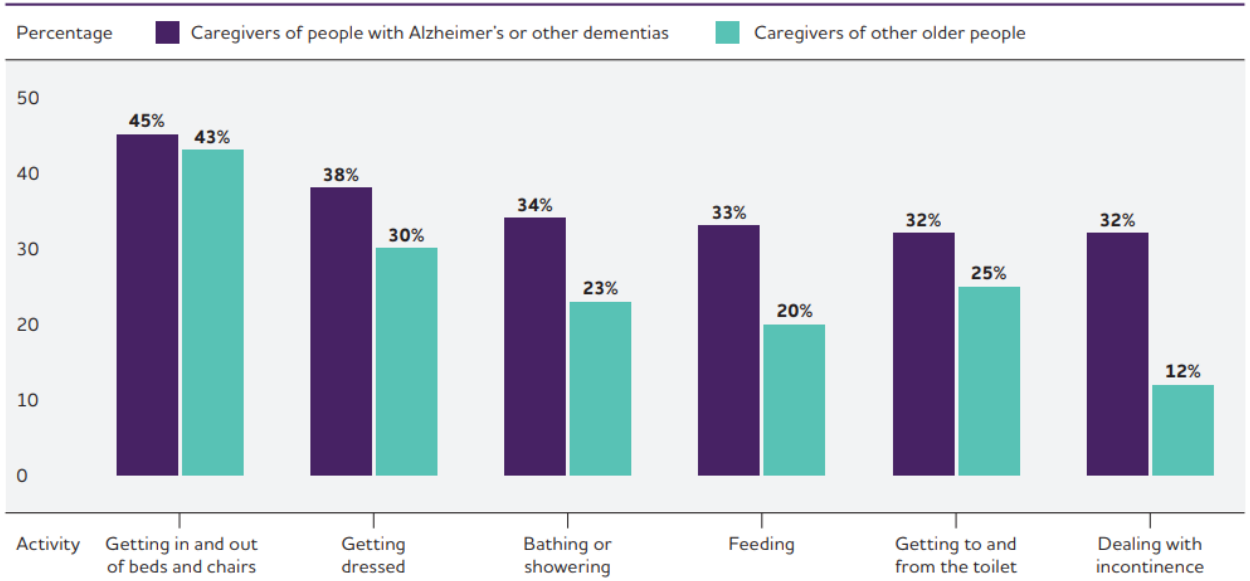
Caregivers indicate

love and a **sense of duty**

as primary motivation for caregiving

Figure **9**

Proportion of Caregivers of People with Alzheimer's or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015



Created from data from the National Alliance for Caregiving in Partnership with the Alzheimer's Association.[442]

Table **11**

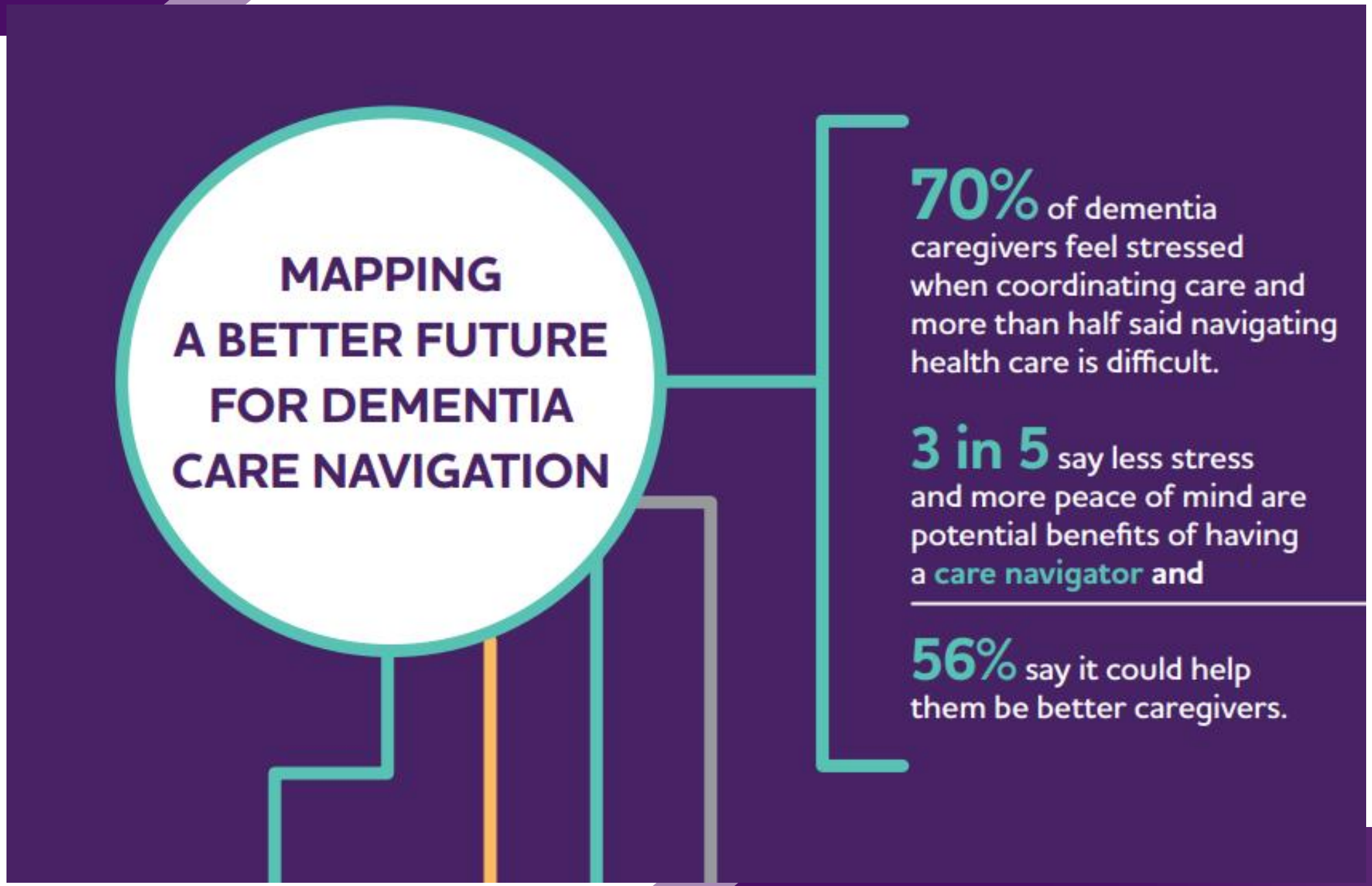
Percentage of Dementia Caregivers Who Report Having a Chronic Health Condition Compared with Caregivers of People without Dementia or Non-Caregivers*

Condition	Dementia Caregivers	Non-Dementia Caregivers	Non-Caregivers
Stroke	5.2	3.4	3.2
Coronary heart disease	8.3	7.2	6.6
Cardiovascular disease†	11.8	9.5	8.6
Diabetes	12.8	11.1	11.3
Cancer	14.3	13.3	11.5
Obesity	32.7	34.6	29.5

*Table includes caregivers age 18 and older.

†Combination of coronary heart disease and stroke.

Created from data from the Behavioral Risk Factor Surveillance System survey.[443]


MAPPING
A BETTER FUTURE
FOR DEMENTIA
CARE NAVIGATION
70% of dementia caregivers feel stressed when coordinating care and more than half said navigating health care is difficult.
3 in 5 say less stress and more peace of mind are potential benefits of having a care navigator and
56% say it could help them be better caregivers.

The Alzheimer's Association® defines dementia care navigation as a program that provides tailored, strength-based support to persons living with dementia and their care partners across the illness continuum and settings to mitigate the impact of dementia through collaborative problem solving and coaching.

Comprehensive Dementia Care Management

- Care management can reduce costs throughout course of disease
- Two pilot programs show potential of ongoing care management

Healthy Aging Brain Center Program (Indiana)

- $3,474 less in health care spending per patient, per year
- Nearly 6:1 return on investment
- Reduced hospitalizations and emergency room visits

Alzheimer's and Dementia Care Program (UCLA)

- $2,100 less in health care spending per patient, per year
- 33% reduction in nursing home placement
- Did not reduce hospitalizations, but reduced intensity of care needed

Caregiver Interventions

- Searchable database of evidence-based interventions for dementia caregivers
  - Sort by language/ type of dementia/ other chronic illness/ cost

SHAPING THE FUTURE OF DEMENTIA CARE NAVIGATION

Comprehensive Care for Alzheimer's Act

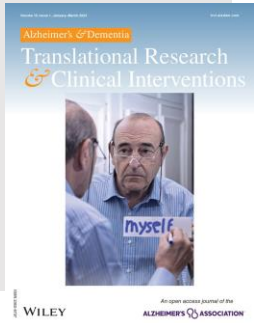
The Comprehensive Care for Alzheimer's Act would ask the Center for Medicare and Medicaid Innovation (CMMI) to test a better payment structure for dementia care management. This model would:

- Provide services such as the development of a dementia care plan, care coordination and navigation, and caregiver education and support.
- Ensure patients have access to an interdisciplinary team of providers with dementia care expertise.
- Reimburse providers through a capitated payment and an incentive payment based on performance.

Dementia Care Navigation Guiding Principles and Roundtable

Alzheimer's and dementia are complex health conditions, and new treatments and health care system barriers add to this complexity. Coordinated care for individuals living with Alzheimer's is fragmented or absent in most settings, particularly in primary care.

To encourage and improve coordinated care, several dementia care navigation programs have been developed.



Guiding an Improved Dementia Experience (GUIDE)

A new voluntary nationwide model – the Guiding an Improved Dementia Experience (GUIDE) Model – a model test that aims to support people living with dementia and their unpaid caregivers.

The GUIDE Model will focus on dementia care management and aims to improve quality of life for people living with dementia, reduce strain on their unpaid caregivers, and enable people living with dementia to remain in their homes and communities. It will achieve these goals through a comprehensive package of:

1) care coordination and care management,
2) caregiver education and support
3) respite services.

CMMI GUIDE MODEL

An eight–year voluntary model

Care Coordination & Management

Beneficiaries will receive care from an **interdisciplinary team** that will develop and implement a **comprehensive, person-centered care plan** for managing the beneficiary's dementia and co-occurring conditions and provide **ongoing monitoring and support**.

Caregiver Support & Education

GUIDE participants will provide a caregiver support program, which must include caregiver skills training, dementia diagnosis education, support groups, and access to a personal care navigator who can help problem solve and connect the caregiver to services and supports.

Respite Services

A subset of beneficiaries in the model will be eligible to receive payment for respite services with no cost sharing, up to a cap of $2,500 per year. These services may be provided to beneficiaries in a variety of settings, including their personal home, an adult day center, and facilities that can provide 24-hour care to give the caregiver a break from caring for the beneficiary.

GUIDE sites launch nationally July 2024

GUIDE REQUIRED PROGRAM CRITERIA

- 24/7 access to support service
- Care coordination and transitional care management
- Caregiver education and support
- Care planning
- Comprehensive assessment and home visit
- Medication management and reconciliation
- Ongoing monitoring and support of the program
- Referral and coordination of social services and support
- Respite services (including in-home respite, adult day centers, and respite in a 24-hour facility)

Age-Friendly Health Systems

Institute for Healthcare Improvement (IHI)/ John A Hartford Foundation initiative to advance evidence-based care of older adults

- Acute Care
- Primary Care
- Nursing Homes

https://www.ihi.org/networks/initiatives/age-friendly-health-systemsHomes

Assess and Act on 4Ms

- What **M**atters
- **M**entation
- **M**edication
- **M**obility

THANK YOU!!!

Doris Phildor, MPH
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Incorporating Caregiver Support into Palliative Care Workflow

Who Provides Palliative Care?

Who delivers palliative care?

Interdisciplinary specialty-trained palliative care teams are comprised of physicians, advanced practice nurses, physican assistants, registered nurses, social workers, and chaplains who all provide expert consultation and co-management. Some teams also integrate services from other disciplines or volunteers.

While palliative care is a subspeciality, the principles and many of the practices of palliative care can — and should — be employed by all clinicians who care for patients living with serious illness.

While Clinicians Focus On Treating The Cause(s) and Symptoms of Dementia, Patients and Caregivers Struggle With…

- Anxiety/worry
- Shortness of breath
- Constipation
- Fatigue
- Stress
- Behaviors*
- Pain
- Eating issues
- Nausea
- Memory problems
- Depression
- Finances

(Source: LCA Needs Assessment Survey, 11/15-2/16)

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Benefits Of Palliative Care

Palliative care benefits include:

- Relief of pain and other symptoms
- Alignment of treatment options to patient priorities
- Increased life expectancy (among some diagnoses studied to date)
- Better communication with patients, as well as families and other caregivers, about what to expect
- Improved care coordination
- Increased family and caregiver support
- Decreased crises, 911 calls, ED visits, and hospitalizations

How Is Palliative Care Paid For

- All this takes time for clinicians to do well
- Billing is the main source for most programs
- Billing opportunities have been created to assist with caring for patients with serous and chronic illnesses like dementia
    - ACP
    - Principal Illness Navigation
    - Caregiver training codes
    - **CPT code 99483**
        - **Provides reimbursement for a clinical visit that results in a comprehensive care plan.**

Effective Interventions

for People Living with Dementia (PLwD) and their Care Partners (CP)

- Informational support
- Emotional support
- Instrumental support

ADI, 2022; Alz. Assoc.2024; Dombrowski et al, 2024

Informational Support

Connect families with sources for ongoing education to help them understand what's happening now and how to prepare for the future.

- Type of dementia (specificities) and stage
- Overview of disease progression
- Discuss what matters most to the person - goals of care now and as condition progresses
- Alert to common symptoms / challenges that may arise (infections, delirium) for earlier intervention
- Explain behavior is communication & teach how to anticipate common unmet needs
- Customize approach strategies to optimize communication, meaningful connection & QOL

Informational Support cont'd.

Provide links to Community Based Resources

Consider cultural, spiritual, social, geographic differences
• Alzheimer's Association & Area Agency on Aging
• Senior Centers
• Faith-based organizations
• GUIDE, COPE, Supportive Care for Dementia program or other dementia-related services in area, hospice when eligible
• Medicaid & assist w/ application process
• Meals, transportation, volunteers

Emotional support - *You don't have to do this alone!*

- Involve the person living with dementia as much as possible & acknowledge care partners play a **vital** role
- Build an interdisciplinary support team to provide comprehensive care
- Participate in support groups (online / in-person) & advocacy groups
- Consider counseling & education re: anticipatory grief & ambiguous loss

Frame as a *collaborative* approach

We will accompany you every step along the way

Instrumental support – Early discussions are crucial

Maximize the person's autonomy and sense of agency, while keeping them and the public safe.

Legal planning	Longer term financial planning	Advance Directives	OT, PT, SLP
Respite opportunities	In-home help	Long-term placement	Spiritual and end-of-life planning

- Discuss while the person has insight and capacity to contribute to decisions and give directions to decision-makers.
- Create and document a supportive framework that honors their choices.
- Periodically check /update the plans & key support persons who will assist.

Observations from working with community providers

Top reasons for dementia-related calls: Medications to "fix" behaviors or sleep

Providers & families feel ill-equipped to decipher causes of behaviors and choose best interventions

- Common preventable or manageable factors (e.g., pain, bowel/bladder, medications, environment, and care partner approaches) are sometimes overlooked
- There is an eagerness to gain expertise in pharmacological and non-pharmacological approaches
  - Beers Criteria for guidance - Esp. effects of anticholinergics (usually for incontinence, allergies and sleep) and benzodiazepines. *J Am Geriatrics Soc*. 2023; 71(7): 2052-2081
  - Improvisational approaches and daily use of sensory / spiritual experiences

Strategies to better integrate and empower caregivers during the clinical encounter

Environment:

How comfortable is the office experience?

How's the wait time?

Knowledge & skills:

Are all staff aware person has dementia?

Do they know basic approach & communication strategies?

Data Collection :

Will the care partner join the person for the appointment

AND

is there opportunity to interview *separately* for additional info and to avoid conflict?

Do you have MPOA contact info in EHR?

Periodic Re-assessments:

Cognitive & Functional status

Do you explain the observed changes so CPs understand and modify care approaches to match current strengths and deficits?

- Communication
- Approach
- Assistance with daily care
- Safety

Strategies to better integrate and empower caregivers during the clinical encounter (cont.)

Review meds to ensure symptom management, prevent complications & align with goals

Do you feel skillful discussing advance directives as they pertain to dementia?

Discuss / document personal life & care goals.

Update EHR care plan/directives

Do you pause to ask the care partners how *they* are doing ?

How to expedite response to urgent issues?

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DEMENTIA CARE and EDUCATION CAMPUS

Hospice of the Valley Resources

https://dementiacampus.org
https://hov.org

Dementia educational videos

https://dementiacampus.org/dementia-resources/

- Topics include dementia progression; behavior as communication; anticipating needs; communication tips; meaningful engagement; Vitamin M (music); best practices in palliative and hospice dementia care; caregiver grief; mindfulness practices & more

- Personalized approaches for 11 interactions that commonly trigger resistance or distress

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DEMENTIA CARE and EDUCATION CAMPUS

HOV Online Care Partner Support Groups
All are welcome

Tuesdays at 10AM AZ time

- Meeting ID: 943 5776 3001 Passcode: 691016

Wednesdays at noon AZ time

- Meeting ID: 955 4998 3607 Password: 562327

Thursdays at noon AZ time

- Meeting ID: 874 8226 4963 Passcode: 401031

FTD Care Partner Support, 2nd Tues of every month 12:30-2:00 PM
Co-sponsored with Banner Alzheimer's Institute

Meeting ID: 929 5954 0200 Passcode: 810344

- Bereavement support for dementia care partners online twice per month (602) 530-6900

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DEMENTIA CARE and EDUCATION CAMPUS

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Q&A

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