

The Role of Hospice and Palliative Care in Alzheimer's Dementia

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Presenter's Bio



Dr. Glen Komatsu earned a BS in biological sciences at the University of Arizona and his MD at the Arizona College of Medicine. After completing a pediatric residence at UC Irvine Affiliated Hospitals and a neonatology fellowship at Long Beach Memorial/Miller Children's Hospital, he entered private practice. He served as Medical Director of the Neonatal Intensive Care Unit at Providence Little Company of Mary Medical Center Torrance from 1985-2004, as well as Director of Bioethics for Providence in the South Bay.

In 2004, Dr. Komatsu pursued the specialty of adult palliative care through a fellowship at Dana-Farber Cancer Institute, Brigham and Women's Hospital, Massachusetts General Hospital and Harvard Medical School. Returning to California in 2005, he now serves as Chief Medical Officer for Providence Hospice Los Angeles and Regional Palliative Care Southern California, Medical Director for Providence Kids Care pediatric hospice and palliative care, Director of the Edmond R. and Virginia G. Doak Center for Palliative Care at Providence Little Company of Mary Medical Center, Torrance, Co-Chair Bioethics, Providence Little Company of Mary Medical Center Torrance and Senior Advisor for Strategy and Education to Providence Institute for Human Caring.

He helped launch Iyashi Care in partnership with Keiro, which provides community-based palliative care services for the Japanese American and Japanese communities in Los Angeles and Orange Counties.

Presenter's Bio

J. Russell Kieffer, LCSW, APHSW-C, is currently the Senior Executive Director of Palliative Care for Providence Health in California, Oregon, & Washington, and has oversight of inpatient, clinic, and community-based adult and pediatric palliative care programming in those states. Prior to accepting the position in 2021, he was the Regional Director in Southern California for Providence palliative care.

A native New Mexican, Russell completed both undergraduate and graduate studies in New Mexico and holds a post graduate certification in Palliative Care Leadership from New York University. He has a 30+-year career history in healthcare and has worked in various medical and educational settings, with an emphasis in HIV/AIDS, hospice, palliative care, and clinical social work.

Russell is an accomplished musician and cycling hobbyist, but currently spends most of his time outside of work raising two young children.

DISCLOSURES

The following CME Planners and CME Faculty do not have any financial relationships with ineligible companies in the past 24 months:

- Leilanie Mercurio, L.A. Care PCE Program Manager, CME Planner.
- Jennifer Schlesinger, Alzheimer's Los Angeles Vice President, Healthcare Services & Professional Training, CME Planner.
- Alicia Villegas, Alzheimer's Los Angeles Director of Healthcare Client Services, CME Planner.
- Glen Komatsu, MD, Regional Chief Medical Officer, Providence Hospice Los Angeles and Regional Palliative Care; Medical Director, Providence Kids Care; CME Faculty.
- J. Russell Kieffer, LCSW, APHSW-C, Senior Executive Director of Palliative Care for Providence Health in California, Oregon, & Washington; CME Faculty.

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

Commercial support was not received for this CME activity.

LEARNING OBJECTIVES

At the completion of the activity, learners can:

1. Describe the FAST (Functional Assessment Staging Tool) scoring system for dementia.
2. Specify the criteria of hospice qualifications for patients with dementia.
3. List and apply strategies to manage Alzheimer's agitation.
4. Summarize ways to support caregiving challenges that families face in caring for loved ones with dementia.



**6 million Americans are
living with Alzheimer's**

**One in nine seniors aged 65
and older have the disease**



Alzheimer's dementia is one of the most challenging diagnoses in hospice and palliative care to predict, treat and support

Global Deterioration Scale - Reisberg Scale

- **Measures cognitive decline**

Functional Assessment Staging Test (FAST)

- **Measures functional decline**

Clinical Dementia Rating

- **Research Tool**

Functional Assessment Staging Test (FAST)

Stage	Patient Condition	Level of Functional Decline	Expected Duration of Stage
Stage 1	Normal adult	No functional decline.	N/A
Stage 2	Normal older adult	Personal awareness of some functional decline.	Unknown
Stage 3	Early Alzheimer's disease	Noticeable deficits in demanding job situations.	The average duration of this stage is 7 years.
Stage 4	Mild Alzheimer's	Requires assistance in complicated tasks such as handling finances, traveling, planning parties, etc.	The average duration of this stage is 2 years.
Stage 5	Moderate Alzheimer's	Requires assistance in choosing proper clothing.	The average duration of this stage is 1.5 years.
Stage 6	Moderately severe Alzheimer's	Requires assistance with dressing, bathing, and toileting. Experiences urinary and fecal incontinence.	The average duration of this stage is 3.5 months to 9.5 months.
Stage 7	Severe Alzheimer's	Speech ability declines to about a half-dozen intelligible words. Progressive loss of ability to walk, to sit up, to smile, and to hold head up.	The average duration of this stage is 1 year to 1.5 years.

Life Expectancy by Dementia Type

Dementia Type	Life Expectancies
<u>Alzheimer's Disease</u>	10 years following diagnosis
<u>Vascular Dementia</u>	5 years following diagnosis
<u>Dementia with Lewy Bodies</u>	2 to 8 years following pronounced symptoms

There are no FDA approved drugs specifically for the treatment of behavioral and psychological symptoms of dementia

Antipsychotics

Drug Class	Potential Indications for Behavioral Symptoms	Benefits for Behavioral Symptoms	Examples and Cost Estimates*	Side Effects and Cautions
Antipsychotics	<ul style="list-style-type: none"> → Short-term treatment of persistent and severe aggression or psychosis, if non-pharmacologic interventions and a trial of analgesics fail → Should <u>not</u> be used to address sleep problems 	<ul style="list-style-type: none"> → Mixed evidence with, at best, modest short-term improvement in behaviors such as aggression or psychosis → Limited evidence for long-term behavioral improvements → No evidence for improved function or quality of life 	<ul style="list-style-type: none"> → Haloperidol (\$20 / 30 1mg tabs) → Olanzapine (\$200 / 30 5mg tabs) → Quetiapine (\$70 / 30 25mg tabs) → Risperidone (\$84 / 30 1mg tabs) 	<ul style="list-style-type: none"> → FDA black box warning of increased risk of mortality in patients with dementia → Increased risk of stroke → Increased cognitive decline → Extrapyramidal symptoms (e.g., Parkinsonism and Tardive Dyskinesia) → Sedation → Increased risk of falls

Pain Medications

Drug Class	Potential Indications for Behavioral Symptoms	Benefits for Behavioral Symptoms	Examples and Cost Estimates*	Side Effects and Cautions
<p>Pain Medications</p>	<ul style="list-style-type: none"> → Pain is a common and important source of behavioral disturbances in patients with dementia → Use interviews and observation to determine whether pain may be contributing to behaviors → Empiric treatment of pain should be considered for individuals with behavioral disturbances without a clear cause 	<ul style="list-style-type: none"> → For those who report or show signs of pain, pain treatment may improve behavioral symptoms → An empiric stepwise protocol starting with a trial of scheduled acetaminophen, then moving to scheduled opioids, has been shown to decrease agitation and aggression in individuals with dementia 	<ul style="list-style-type: none"> → Acetaminophen → Morphine (\$60 / 120 15mg tabs) → Oxycodone (\$91 / 120 10mg tabs) 	<ul style="list-style-type: none"> → Opioids can increase risk for falls → Constipation is a near universal side effect of opioid therapy and should be treated proactively with a bowel regimen → Start low, go slow → Dose adjust based on impact on behavior and function

Benzodiazepines

Drug Class	Potential Indications for Behavioral Symptoms	Benefits for Behavioral Symptoms	Examples and Cost Estimates*	Side Effects and Cautions
<p>Benzodiazepines</p>	<p>→ Should be limited to care at the very end of life, where sedation is the goal and cognitive/functional side effects are acceptable</p>	<p>→ While there may be modest, short-term benefits with agitation due to sedating effects, the risks of worsening confusion, delirium, and falls generally outweigh any benefit</p>	<p>→ Lorazepam (\$14 / 30 0.5mg tabs)</p> <p>→ Oxazepam (\$32 / 30 10mg tabs)</p> <p>→ Temazepam (\$20 / 30 15mg tabs)</p>	<p>→ Sedation</p> <p>→ Paradoxical agitation</p> <p>→ Delirium</p> <p>→ Worsening cognition</p> <p>→ Increased risk for falls and fractures</p>

Cholinesterase Inhibitors and Memantine

Drug Class	Potential Indications for Behavioral Symptoms	Benefits for Behavioral Symptoms	Examples and Cost Estimates*	Side Effects and Cautions
<p>Cholinesterase Inhibitors and Memantine</p>	<ul style="list-style-type: none"> → Should not be considered for first-line treatment of moderate to severe behavioral symptoms in dementia → Consider use in mild symptoms as an adjunct to non-pharmacologic therapy 	<ul style="list-style-type: none"> → Studies have shown a very small benefit in behavioral symptoms in dementia, though clinical significance is questionable → Benefit may be more clinically significant in patients with Lewy Body Dementia 	<ul style="list-style-type: none"> → Donepezil (\$200 / 30 10mg tabs) → Galantamine (\$160 / 60 4mg tabs) → Rivastigmine (\$230 / 60 1.5mg tabs) → Memantine (\$280 / 60 10mg tabs) 	<p>Cholinesterase Inhibitors (Donepezil, Galantamine, Rivastigmine):</p> <ul style="list-style-type: none"> → Nausea, vomiting, diarrhea, weight loss, anorexia, insomnia, bradycardia <p>Memantine:</p> <ul style="list-style-type: none"> → Dizziness, headache, constipation, fatigue

Dextromethorphan-Quinidine

Drug Class	Potential Indications for Behavioral Symptoms	Benefits for Behavioral Symptoms	Examples and Cost Estimates*	Side Effects and Cautions
<p>Dextromethorphan - Quinidine</p>	<p>→ Avoid until more data support safety in dementia</p>	<p>→ Limited evidence outside of one randomized control trial showing modest benefit with agitation in dementia</p>	<p>→ Dextromethorphan - Quinidine (Nuedexta) (\$1,200 / 60 20mg/10mg capsules)</p>	<p>→ Falls</p> <p>→ Diarrhea</p> <p>→ Dizziness</p> <p>→ Cost prohibitive for many patients</p>

Mood Stabilizers

Drug Class	Potential Indications for Behavioral Symptoms	Benefits for Behavioral Symptoms	Examples and Cost Estimates*	Side Effects and Cautions
<p>Mood Stabilizers / Anticonvulsants</p>	<p>→ Limited role for treatment of behavioral symptoms due to lack of evidence and risk for side effects</p>	<p>→ Large, well-controlled randomized trials, as well as meta-analyses, have not supported use for agitation, aggression, or other behavioral symptoms</p>	<p>→ Depakote (\$227 / 60 250mg tabs)</p> <p>→ Lamotrigine (\$70 / 30 100mg tabs)</p> <p>→ Valproic Acid (\$80 / 120 250mg tabs)</p>	<p>Depakote: → Nausea, GI upset, ataxia, sedation, hyponatremia</p> <p>Lamotrigine: → Skin rash, Stevens-Johnson syndrome, dizziness, sedation, neutropenia, anemia</p> <p>Valproic Acid: → Sedation, falls, diarrhea, ataxia, weight loss, thrombocytopenia</p>

SSRIs

Drug Class	Potential Indications for Behavioral Symptoms	Benefits for Behavioral Symptoms	Examples and Cost Estimates*	Side Effects and Cautions
<p>Selective Serotonin Reuptake Inhibitors (SSRIs)</p>	<ul style="list-style-type: none"> → Use for treatment of persistent agitation if non-pharmacologic interventions fail → Use for treatment of depression and anxiety, for both patient and caregiver 	<ul style="list-style-type: none"> → Modest benefit for agitation behaviors in randomized control trials → May have benefit for concurrent depression and anxiety 	<ul style="list-style-type: none"> → Sertraline (\$40 / 30 100mg tabs) → Citalopram (\$30 / 30 20mg tabs) → Escitalopram (\$90 / 30 10mg tabs) 	<ul style="list-style-type: none"> → GI upset → Falls → Hyponatremia → Delirium → Potential small decline in cognitive function

Sleep Disturbances in Dementia

Non-pharmacologic interventions are the first line therapies for sleep problems in dementia.

Patient, thoughtful, kind staff

- *Nurses*
- *Admission Staff and Afterhours Staff*
- *SWs*
- *Chaplains*
- *Physicians*
- *NPs*
- *Volunteers*
- *Bereavement Staff*

Whole Person Care

- *Presence*
- *Patience*
- *Support*
- *Compassion*
- *Love*



Nonpharmacologic Strategies for Management of Alzheimer's Agitation

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- ❑ Pharmacological interventions have been traditionally used in the treatment of agitation, but many studies have documented adverse effects of sedative and antipsychotic drugs, such as worsening cognitive function, higher cerebrovascular side effects, longer hospitalizations, and increased mortality.
- ❑ There appears to be a relationship between agitation and unmet needs originated by a decreased ability to cope with environmental stimulation and to communicate these needs.
- ❑ The use of a nonpharmacological approach as a first-line treatment for agitation in dementia patients has been increasingly recommended.
- ❑ Overall, however, evidence-based studies on non-pharmacological interventions are lacking.



Nonpharmacological approaches address the contextual and/or psychosocial reasons for agitation and avoid the potentially negative side effects of pharmacological treatment.

Interventions can include, but are not limited to:

- Therapeutic touch
- Aromatherapy
- Bright light therapy
- Music therapy
- Multisensory stimulation
- Exercise – walking, dancing, movement
- Pet therapy
- Cooking
- Psychological/behavioral interventions with family caregivers

In general, there is a severe paucity of research into the effects of nonpharmacological therapies in managing agitation.

Music therapy is optimal for the management of agitation in institutionalized patients with moderately severe and severe AD, particularly when the intervention includes individualized and interactive music.

Supporting the Family and Caregivers of People Living with Dementia



There are only four kinds of people in the world - those who have been caregivers, those who are caregivers, those who will be caregivers and those who will need caregivers.

— *Rosalynn Carter* —

AZ QUOTES

A typical day in the life of Carmen:



Carmen represents one of more than 16 million family and other unpaid caregivers of persons living with dementia in the United States.

In 2017, these caregivers provided over 18 billion unpaid hours of assistance with self-care or household activities to older adults with dementia.

Despite the vital role caregivers play in dementia care, many clinicians are unsure how best to support them.



someone in the
U.S. develops
Alzheimer's disease

In 2023, total payments
for all individuals with
dementia are estimated at



Caregiver strain leads to
increased health care costs
of more than

\$1,300

**PER CARE RECIPIENT⁵
AND**

**\$4,766
more**

per year per person
FOR CAREGIVERS THEMSELVES⁶

Annual Medicaid payments for
beneficiaries with dementia were



22



TIMES HIGHER
than for those without dementia⁴

Who provides the vast majority of care for older adults living with dementia?

Unpaid friend or family caregivers

Paid home health workers

Healthcare professionals

Most persons living with dementia are cared for in their homes and depend upon care from family, friends, neighbors, and other unpaid help for complex care needs over the long course of the disease. The economic value of this unpaid caregiving dramatically surpasses spending for formal home health care and nursing home care. Accounting for all costs (out of pocket and others), the *annual* societal cost attributed to dementia is \$56,290

Who are the caregivers of individuals with dementia?

Relatives

Partners

Friends

Neighbors

Caregivers are not necessarily related to the caregiver. A caregiver may be any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition.

more about caregivers...

How individuals end up in caregiving roles is shaped by existing relationships, gender roles, cultural norms and expectations, as well as a host of other factors.

For example, lesbian, gay, bisexual, and transgender (LGBT) individuals are more likely to care or be cared for by a non-relative than non-LGBT individuals.

Caregiving requires many tasks, all of which must be done while juggling other responsibilities such as childcare, daily errands, or working full- or part-time jobs.

Caregiver tasks include...



Household tasks



Activities of daily living, safety, and behaviors



Emotional and social support



Health and medical care



Advocacy and care coordination



Surrogate decision-making

Impact of Caregiving on the Caregiver

Increased rates of depression

Decreased self-rated physical health

Increased financial burden

Improved sense of confidence in dealing with difficult problems

Caregivers are often thrust into this position, with no training and little support, resulting in increased prevalence of adverse physical, financial, social, and psychological outcomes. However, the effects of caregiving are variable, depending on characteristics intrinsic and extrinsic to the individual, and may simultaneously include positive aspects as well, such as an improved sense of confidence in dealing with difficult problems.

more about caregivers...

Caregiver burden is an all-encompassing term used to describe the physical, psychological, social, and financial toll of providing care.

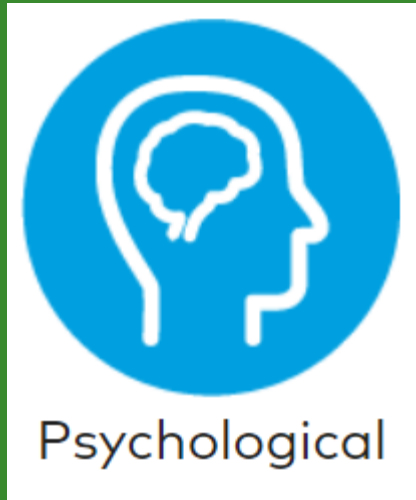
Caregivers of home-dwelling elderly patients with dementia report more physical and psychosocial burden than their peers of the same age and living circumstances.

Caregiver burden is also associated with important health care utilization outcomes, including risk of emergency department utilization and nursing home placement for patients with dementia.

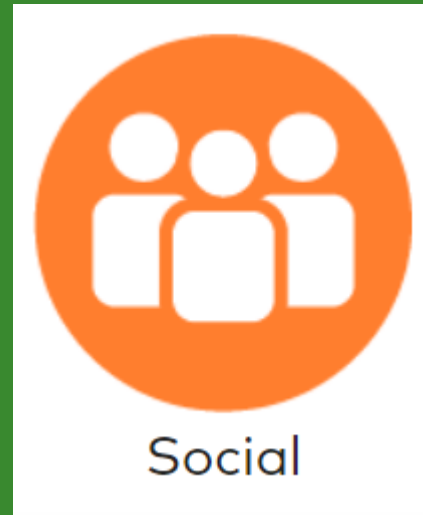
Consequences of caring for individuals with dementia...



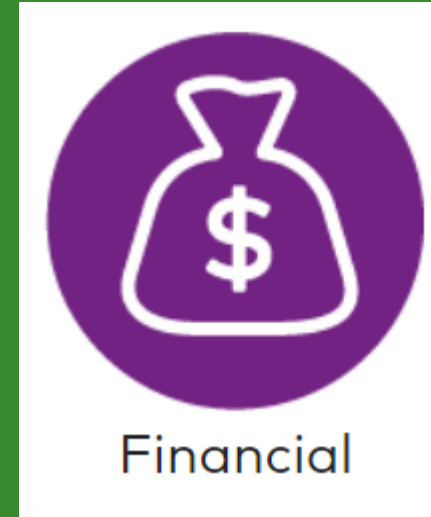
Physical



Psychological



Social



Financial

Risk factors for negative consequences of caregiving

- Intensity of caregiving
- Lack of choice in taking on the caregiving role
- Caregiver's physical condition
- Caregiver's social supports

Many factors increase the risk for negative consequences of caregiving, including the intensity or type of caregiving, lack of choice in taking on the caregiving role, the caregiver's health and physical functioning, and their social and professional supports..

How you can help caregivers

What do caregivers want from their clinicians?


Information about their loved ones
medical care

Information about dementia progression

Emotional support

Referral to services that relieve burden, such as respite care

Caregivers often receive inadequate support from health professionals and frequently feel abandoned and unrecognized by health care systems. Half of caregivers of older adults with dementia report that they provide medical and nursing tasks without prior preparation. Caregivers express a desire to be involved in their loved one's medical care, to have recognition of the importance of their caregiving role, and for information about the diagnosis of dementia and ongoing assistance after the diagnosis. Caregivers often state that they want more information about their loved one's illness and symptoms, referral to support services, and emotional support. *Only a quarter of caregivers have ever been asked about their own self-care needs.*



YOU'VE BEEN DOING A REMARKABLE JOB
HELPING ROSA. TELL ME HOW THINGS
ARE GOING FOR YOU.

✚ Providence

3 Steps for Clinicians Supporting Caregivers

Step 1. Include the caregiver as a member of the care team.

- Many individuals who provide care to older adults with dementia do not think of themselves as a caregiver; rather, they identify in terms of their relationship with the person who has dementia (i.e. spouse, daughter, neighbor).
- The first step is to acknowledge and validate what they do in their role caring for the individual with dementia.

First, identify who is providing the person with dementia.

Include the caregiver's name and contact information in the caregiver's chart.

Include the caregivers in medical visits, not just at the crisis or when important decisions need to be made.

3 Steps for Clinicians Supporting Caregivers

Step 2. Ask about the caregiver's health and well-being, not just About the patient's

- At Rosa's last doctor's appointment, her doctor noticed that Carmen looked exhausted and jittery. The doctor wanted to ask whether she was doing okay, but was afraid of overstepping his boundaries because Carmen wasn't his patient.

What is the clinician's responsibility in this case?

It's an ethical obligation to ask how she's doing

He should ask only if Carmen has concerns.

He should ask only if Rosa brings up concerns

Don't ask—Carmen is not the provider's patient

3 Steps for Clinicians Supporting Caregivers

Step 3. Address Caregiver's Needs

- It may feel overwhelming to address the needs of both the patient and the caregiver.
- If you work as part of a team, determine who on the healthcare team will be responsible for addressing the needs of the caregivers.
- Depending on your setting and resources, this may include a nurse, social worker, case manager, nurse practitioner, or physician.



Key areas to address



Provide
Emotional
Support

Provide Emotional Support

- Caregivers' needs and feelings matter. Your validation of their role and effort can be essential to their self-worth and confidence.
- Encourage caregivers to maintain a life outside of caregiving and to take care of their own health.
- Connecting caregivers to support groups is an underutilized but important way to meet their emotional needs.



Key areas to address



Provide
Caregivers
with
Education
and
Information

Provide Caregivers with Education and Information

- The clinician should meet with the caregiver regularly to provide education and information on diagnosis, clinical updates on what to expect as dementia progresses, treatment options, and management strategies.
- It is helpful to have printed educational resources and guidance to provide to patients and caregivers, and provide them as a prescription as appropriate.



Key areas to address



Make the
Referral
Yourself

Make the Referral Yourself

- Many caregivers are unlikely to find and initiate support services on their own.
- It is best to make direct referrals to community organizations that provide services that meet the particular needs of each patient and their caregivers, including counseling, respite care, and adult day care.
- When community supports are provided as a doctor's order or prescription, caregivers are much more likely to follow up and make use of them.

The first referral should be to the Alzheimer's Association.

The Alzheimer's Association is a nationwide source of evidence-based and practical information about all aspects of care for people living with dementia and their caregivers. The organization's local chapters provide care consultation, support groups, 24/7 support line services, education, and safe return programs.

• **What to do:** Hand caregivers a prescription to call the Alzheimer's Association's 24/7 national helpline at 1-800-272-3900 or visit their support web pages.

• Providers can [order referral pads](#) or download the Alzheimer's Association [Pocketcard App](#) online.

Evidence indicates that multicomponent interventions, rather than singular interventions like one-time education, have the greatest impact on caregiver quality of life

Resources vary widely from one community to the next. But even in resource-limited settings clinicians can provide a wide range of support:

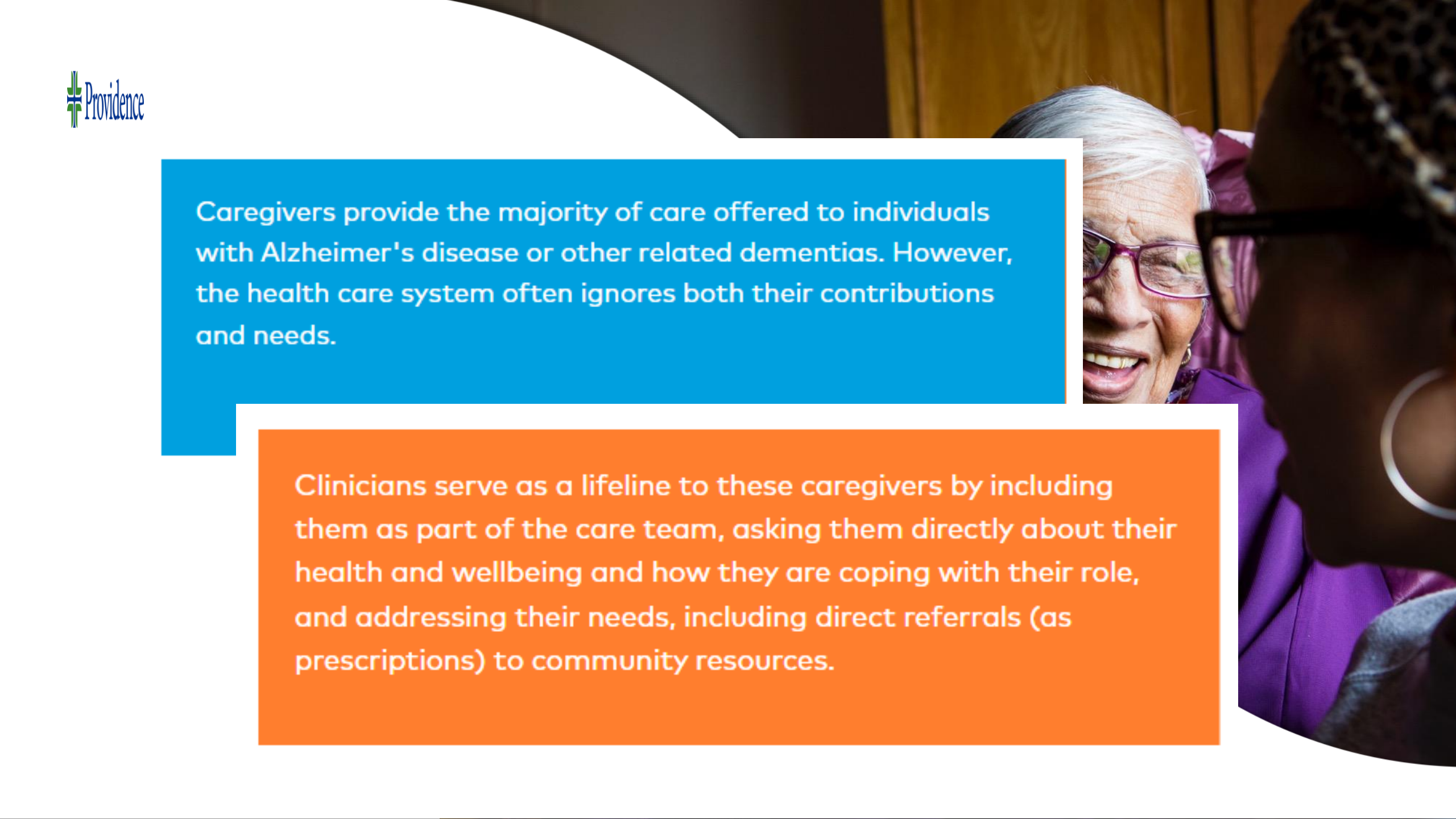
- Respite care
- Legal aid
- Home-delivered meals (Meals on Wheels)
- Adult day centers
- Home health care
- Hospice
- Support groups



Organizations like the [Alzheimer's Association](#) or the [Family Caregiver Alliance](#) offer free skills training, and other educational opportunities at local and national levels.

LGBT face unique caregiving challenges. [SAGE](#) offers information and support for this group of caregivers.

Veterans and their caregivers may have access to additional resources offered by the [Department of Veterans Affairs](#), the Caregiver Support Line, home care, and respite care.

A background image showing an elderly woman with white hair and purple glasses smiling, and a man in a dark suit and glasses looking towards her. The image is partially obscured by text boxes.

Caregivers provide the majority of care offered to individuals with Alzheimer's disease or other related dementias. However, the health care system often ignores both their contributions and needs.

Clinicians serve as a lifeline to these caregivers by including them as part of the care team, asking them directly about their health and wellbeing and how they are coping with their role, and addressing their needs, including direct referrals (as prescriptions) to community resources.

Failure to address the unmet needs of people facing dementia could bankrupt our health system.



Through better identification, assessment, and support of people with cognitive impairment and their caregivers, we can reduce health care spending and improve quality of life.

Learn more and get started:

capc.org/dementiatoolkit

Frequently Asked Questions (FAQs)

1. When should a patient be referred to palliative care?

Answer: When the patient and family are struggling to care for patient, when the patient and family are seeing the need to have a goals of care discussion, when patient is having symptoms not well managed, when patient and/or family requests a palliative care consultation.

2. When should a patient be referred to hospice?

Answer: When the family agrees with a hospice referral, and FAST score reaches 7 or if patient has a lower score but another illness with an expected prognosis of 6 months or less.

Frequently Asked Questions (FAQs)

3. How can behavioral disturbances be managed with Alzheimer's?

Answer: No medication works for every patient with dementia related agitation but the general class of medications most helpful are the anti-psychotic medications. Non-pharmacologic techniques can also be very helpful.

4. How can families and caregivers be supported?

Answer: Multiple community resources through the Alzheimer's Association, palliative care and hospice programs, group, and individual therapy.

Thank you!

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