



Living Well with Dementia

Image credit: Hospice of the Valley

Dr. Maribeth Gallagher

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Seniors today are nothing like those of previous generations. They are more active, more health-conscious and have a more youthful mindset. All these attributes enrich their lives — and also help them *live longer*. It seems a contradiction: Age is the single biggest risk factor for Alzheimer’s disease and related dementias (ADRD).

Today, more than 6.5 million Americans (50 million worldwide) are affected by ADRD. With Arizona seeing one of the highest growth rates of dementia in the nation, it will continue to be a leading cause of disability and death among older adults in the Grand Canyon State.

This is a reality that many face as they struggle to care for someone they love with the disease. Most have no idea how to be a caregiver. As troubling: Most have no understanding of the dementia journey. They quickly find that this challenging disease affects the entire family. Most care is delivered by relatives and close

friends who want to keep their person home for as long as possible. Without support, the health and well-being of caregivers often suffer, despite their best efforts to provide care and oversight.

Providing good dementia care is complicated. Each experience is a highly individualized journey. There's no predicting precise timelines or behaviors that will occur as the condition progresses. The long course of dementia leads to changes that can be bewildering, frustrating and overwhelming.

Along the way, caregivers will also experience moments that are surprisingly profound, meaningful and rewarding. When equipped with information, insight and support, people living with dementia and their care partners are better able to manage their own health and focus on what matters most — quality of life.

There is support. Caregivers need not journey alone.

To meet the critical need for dementia support, Hospice of the Valley (HOV) has launched innovative programs to help people live well with dementia. The

Supportive Care for Dementia program and new Dementia Care and Education Campus both focus on education, resources, effective coping strategies, encouragement and ongoing support.

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Supportive care for dementia

The HOV in-home Supportive Care for Dementia (SCD) program is provided at no charge to persons living with dementia and to family members who are caring for loved ones — from pre-diagnosis through the early and middle stages of dementia. People living with early stages of dementia struggle with knowing what lies ahead and how to move forward. Care partners experience stress, anger and grief — and over time, may become isolated and depressed.

Skilled dementia educators provide valuable support, making home visits to educate and empower the person with dementia who lives alone or with family, as well as their caregivers. Compassionate, knowledgeable teams demonstrate and teach new ways to stay connected during each stage, providing practical tools to

enhance quality of life. They help celebrate the person who still is present and offer support to cope with losses along the way.

Mind, body, spirit

The Dementia Care and Education Campus created at HOV provides comprehensive and holistic care — focusing on body, mind and spirit. Families are supported through the early, moderate and advanced stages of dementia with education, socialization and compassion. Breaking new ground for ADRD patients and caregivers alike, this innovative campus and leading-edge care has also inspired careers in dementia care and is helping build a dementia-capable workforce for the future. In support of the greater community, the campus brings exceptional care and vital resources together in one place.

The Dementia Care and Education Campus also features an education center where frontline caregivers, senior healthcare professionals and industry leaders can come together to share best practices in dementia care, while ensuring purposeful opportunities through the maintenance of a recognized program of events and classes that facilitate and encourage meaningful interactions among attendees.

Additional encouragement and assistance for caregivers is available through the HOV Memory Café Support Group at no charge. Here, attendees receive compassionate support and learn to manage stress and promote self-care throughout the dementia journey — while in a nearby room, trained dementia caregivers engage their loved ones in socialization and fun activities.

The intergenerational Adult Day Center provides a sense of community for those living with dementia, respite for caregivers, and meaningful interaction with preschoolers in the adjoining Child Center. Studies show intergenerational connection creates joyful benefits for both young and elderly.

A small Assisted Living Center and a Dementia Hospice Inpatient Home specialize in superb dementia care for residents, patients and family members -- providing 24/7 clinical support.

Educating healthcare providers

While providing exceptional care and comprehensive support is critical in ADRD settings, the training of current and future dementia professionals must also be addressed in meaningful and effective ways. There is a severe shortage of providers skilled in dementia care. The number of those trained and competent is not nearly sufficient to support the large and growing senior population in the future.

The lack of senior healthcare professionals trained in dementia care will impact all of us.

In response to the need for additional quality support, Hospice of the Valley's Dementia Care and Education Campus offers an unprecedented education project aimed at training more than 3,000 health providers through the end of 2023, an effort designed to enhance dementia care for those with early and moderate stages of the disease. The extensive campaign is being funded by the Maricopa County Department of Public Health.

According to the 2022 Alzheimer's Association report, "[Alzheimer's Disease Facts and Figures](#),"¹ half of all primary care physicians feel the medical is mostly unprepared to effectively serve the burgeoning numbers of people living with dementia. HOV Dementia Care Program Director Dr. Maribeth Gallagher, a nationally and internationally awarded dementia specialist and collaborator in healthcare industry innovations, says, "There is a tremendous and critical need for dementia care education and training that will help providers deliver evidence-based skillful and compassionate care. That need will only grow as the incidence of dementia rises each year."

The HOV education project covers a wide variety of topics, from assessing and diagnosing mild dementia to understanding which medications help or harm dementia patients. Presentations also provide doctors practical tools they can share with family caregivers, such as the soothing effects of "Vitamin M" — music — or ways to decode behaviors that express unmet needs like fear, anxiety or pain.

1 National Institute on Aging (NIA), "Tips for Living Alone with Early-Stage Dementia," National Institute on Aging (NIA). Accessible from <https://www.nia.nih.gov/health/tips-living-alone-early-stage-dementia#every-day-tasks>.

Dr. Ned Stolzberg, HOV executive medical director, is confident this unique training opportunity will be widely embraced. A recognized voice in the importance of quality hospice care, Stolzberg says, “Having been in primary care myself, I know how helpless physicians, nurse practitioners and physician assistants can feel when confronted with patients struggling with dementia, not only problems related to diagnosis and treatment, but also the myriad challenges that arise in the social realm. Awareness of even the basic tools to address some of this will greatly empower our medical community.”

The new initiative focuses exclusively on medical professionals, enabling them to help their patients manage early and moderate stages of the disease with knowledge and dignity.

“We can inspire and educate providers — and through them, families — to improve quality of life for people living with all types and all stages of dementia,” says Dr. Gillian Hamilton, medical director of HOV’s Supportive Care for Dementia program. “Physician offices are the first stop for families concerned about memory loss, and how they talk to families sets the stage for the whole journey through dementia.”

Enhancing communication

One of the most challenging aspects of living with dementia, for both family caregivers and medical professionals, is communication. As parts of the brain start to atrophy, people are unable to function as they once did – leading to frustration

and confusion for all. Hospice of the Valley’s Supportive Care for Dementia program strives to help people maintain connection while preserving the dignity of the person with dementia.

Fortunately, there are a number of practical tools that can make a positive difference in a patient’s life.

The most important thing care partners

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and medical professionals can do is to let go of the natural reflex to correct or reason with someone who is living with dementia. *Their reality* is every bit as real to them, as yours is to you. Agreeing in a calm, nonjudgmental way with what they are seeing, hearing and saying reduces stress for you and makes the person feel safe.

It may also help to try a concept called “validate, connect and redirect”:

- Begin by offering validation with a “yes” or nod of the head so the person feels understood.
- Find a way to instill connection rather than opposition.
- Redirect the conversation to something pleasant. For example, when a person insists, “I want to go home!” it may not be helpful to say, “No, you live here. Don’t you remember?” Instead, try to:
 - Validate: “Yes, you want to go home.”
 - Connect: “And I want to help you.”
 - Redirect with a pleasant sensory experience: “Let’s have a snack before we go.”

These additional tools may also enhance communication:

- Always acknowledge the person’s feelings because emotional memory usually stays intact the longest. If you notice anxiety, perhaps say, “You look upset/scared.” Reassure, by saying, “I will keep you safe” or “I’m so glad I can stay with you.”
- Visual cues often work more powerfully than words alone. Use a picture or point to the object or person you are referring to.
- Use gestures to get your message across. Try greeting the person by name and signaling with a “hello” sign to trigger deeply embedded social responses.
- Approach the person from the front. Identify yourself (when needed) and maintain good eye contact (unless it’s culturally inappropriate). Reposition to eye level if the person is seated.
- Call your person by their preferred name. Old nicknames may be more familiar

as memory fades.

- Touch can communicate warmth, safety and love. Consider holding hands, putting your arm around the person, softly touching the arm or giving a gentle massage.
- Play favorite songs. Music is a universal way to provide comfort that is easily understood.
- Always answer the question as if it's the first time; for the person asking, it is.
- Create a calm environment and minimize or eliminate distractions, such as TV or radio.
- Show signs of caring in your tone of voice and facial expressions, but be careful to avoid “elderspeak,” which refers to speech that “infantilizes” older adults.
- Be aware that body language is often well understood by persons with dementia. Sensitive to the emotions of others, they may mimic emotions like sadness or anxiety.
- Simplify your conversations and allow enough time for your message to sink in. It may take up to a minute to get a response.
- Positive direction prevents confusion for someone struggling with questions or choices. “Let’s go to lunch,” instead of “Would you like to go to lunch?”
- Avoid using the word “no” because a person living with dementia experiences “no” in many forms over the course of a day/week. Studies show this can result in aggression, resistance, depression and withdrawal.

As dementia progresses, it will become more difficult for someone with dementia to make their needs known. Care partners who stay alert to communication challenges can successfully adapt. Tapping into familiar social skills, as well as using all the other senses, allows connections to be made.

You are not alone on the dementia journey

Despite the profound changes that occur as dementia progresses from early to

advanced stages, there are still ways to find meaning, purpose, connection and joy in living. This depends largely on the knowledge and skills that care partners develop as they strive to honor, understand and anticipate the unique needs of persons living with dementia.

Each interaction, even in the tiniest of moments, offers opportunities to reflect and affirm the individual's dignity, value and personhood. Many families and loved ones are on this same challenging journey, and it can be empowering to travel it together.

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About the Author

Dr. Maribeth Gallagher is a nationally and internationally awarded dementia specialist focusing on hospice and palliative care, therapeutic applications of music, and mindfulness meditation practices. An experienced program director with a demonstrated history of successfully collaborating in national health care industry innovations, she is a board-certified psychiatric nurse practitioner with a Doctor of Nursing degree. She is a fellow of the American Academy of Nursing, and has been selected to serve as an advisor to U.S. federal agencies on dementia care policy improvements. Dr. Gallagher is the director of dementia programs at Hospice of the Valley, Arizona's leading provider of end-of-life care and one of the country's oldest and largest not-for-profit hospices.