



Making a Difference in Memory Care

New approaches offer hope
for people living with memory loss.



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— Rachel Main,
Director of Memory Care and Life Enrichment at Elder Care Alliance

The numbers are staggering: Almost **8 million new cases of dementia** are diagnosed worldwide every year. That's **1 new case every 4 seconds**.¹ As the U.S. population ages, the number of people at risk for dementia and Alzheimer's disease increases. The diagnosis can be devastating. Almost immediately, most people think about all they will lose. Yet as researchers learn more about memory loss and the effectiveness of interventions, the public narrative is evolving from one of despair to one of hope—and so is the outlook of those affected and their loved ones.

John Zeisel, Ph.D., author of the book, "I'm Still Here: A New Philosophy of Alzheimer's Care," has been at the forefront of this shift for more than two decades. "We define hope

as the ability to make a difference in the lives of people living with dementia," said Zeisel, who provides training programs on non-pharmacologic approaches to memory care through the Hearthstone Institute.

Elder Care Alliance's fundamental philosophy is that while cognitive skills may diminish, every person still has the ability to grow and learn.

"Memory care is about engagement and finding meaning by focusing on the strengths that remain," said Rachel Main, Director of Memory Care and Life Enrichment at Elder Care Alliance. "When you focus on those strengths, you can really help people live a quality life by living in the present."

Nearly 40% of people age 85 and older have Alzheimer's disease. In California, 580,000 people were living with the disease in 2014—that number is expected to grow to 840,000 by 2025.ⁱ

Dementia Defined

Memory loss that affects a person's ability to perform everyday activities is called dementia. Dementia is not a disease but rather a set of symptoms. In addition to memory loss, these can include personality and behavioral changes along with difficulty in reasoning, speaking, learning and performing physical tasks.^{iv}

Alzheimer's can cause dementia, but dementia can also result from injuries that affect the brain, including stroke and head trauma.^{iv} There's no cure for dementia or Alzheimer's today, but advances in approaches to care are helping seniors achieve a better quality of life.

The Alzheimer's Association identifies some of the more common types of dementia:

Alzheimer's is the most common form, accounting for 60 to 80 percent of all cases. Symptoms range from difficulty remembering names or recent events in the early stages to confusion and decline in physical functioning in later stages. While most people diagnosed with Alzheimer's are over age 65, early-onset Alzheimer's affects up to 5 percent of the more than 5 million Americans with the disease.^v

Dementia with Lewy bodies is the second-most common type of dementia. People with this form of dementia often experience hallucinations and fluctuations in alertness. The disease can be difficult to diagnose because "dementia with Lewy bodies, Parkinson's disease and Parkinson's disease dementia may be linked to the same underlying abnormalities in brain processing of alpha-synuclein as Alzheimer's," according to the Alzheimer's Association.^{vi}

Frontotemporal dementia is a group of disorders caused by degeneration of the cells in the area behind the forehead and ears. It often leads to dramatic changes in personality and behavior. Those with a family history of the disease are most at risk. This disorder accounts for up to 10 to 15 percent of all dementia cases.

Vascular dementia is often caused by a stroke or blocked blood vessel. Symptoms may involve difficulty with judgment or decision-making. Risk for this type of dementia is greatest in smokers and those with high blood pressure and high cholesterol.

Mixed dementia involves multiple conditions that contribute to symptoms. Vascular dementia and Alzheimer's disease occur together most commonly.



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Facing the Challenges Ahead

In the U.S., 76 million baby boomers are creating a “silver tsunami”— sparking significant ramifications in both the demand for senior living in general and memory care services in particular. Interest in how that care is delivered is also growing.^{vii}

Effective memory care services center on the vitality of the person, with caregivers focusing on those abilities that don’t diminish with the progression of the disease. “With dementia comes a whole host of mental, emotional and physical challenges,” said Main. “The goal is to provide holistic medical care and psychosocial support to keep seniors as engaged as possible.” Comprehensive memory care services draw on research and practice guidelines from many fields, including geriatrics and gerontology, neuroscience, nursing, social work,

occupational and physical therapy, and incorporate the importance of behavioral and spiritual health.

Since the mid-1980s, the field of memory care has been moving toward practices and methodologies that focus on the individual, not the disease.^{viii} This person-centered approach uses the cultural background and life story of each individual as a starting point. From that frame of reference, care and services focus on nurturing the abilities and interests still present even as cognitive function declines.

The focus is on promoting activities and interactions that enhance quality of life, foster personal growth, and encourage meaningful engagement with care partners, family, friends and community.

Changing the Narrative

The I'm Still Here™ approach focuses on addressing irritability, aggression, apathy and anxiety, behaviors that were once thought of as untreatable symptoms of Alzheimer's and related dementias. "All of these symptoms increase when people are abandoned to the medical system, and they lose their relationships with the people who love them," said Zeisel.

Caregivers trained in the I'm Still Here approach learn to read these behaviors (often termed "negative") as indications that an individual's needs are not being met. Caregivers can then respond by offering activities that engage the individual in an emotionally satisfying way, which causes the behaviors to subside.

Non-pharmacologic approaches to memory care, such as I'm Still Here, not only improve outcomes over time for people living with memory loss, but also reduce caregiver stress. For example, a six-month study by the Gerontological Society of America revealed that participants with dementia in specialized adult day services showed significantly fewer depressive behaviors than those who didn't participate, despite the progression of memory loss.^x Caregivers in the study also reported a reduction in their own stress levels.

The I'm Still Here Foundation maintains that these successes happen when caregivers change the narrative, approaching individuals with dementia from a perspective of hope. Instead of

focusing on a person's inability to recall the date or the name of the president of the United States for example, caregivers celebrate and reinforce moments when people remember loved ones or life events that matter to them. The idea is to acknowledge and appreciate moments when people experience joy, being present and engaged in an activity. While it may seem people with memory loss have a short attention span, they'll often focus for long periods of time on events and conversations meaningful to them.

The Montessori method, originally developed for young children, is also gaining traction among Alzheimer's caregivers interested in an individualized, patient-centered approach to care.^x In Montessori schools, teachers create lessons and activities that most appeal to the students' interests and are specifically designed to engage their senses. The theory is that the more ways students connect with the world, the more their brains engage.

Montessori-based methods of dementia programming have a similar goal: engage the senses to help Alzheimer's and dementia patients and loved ones rediscover the world around them. For example, residents of one Elder Care Alliance memory care community made blankets for babies in the neonatal unit of a nearby hospital. Some sorted fabrics and patterns while others sewed. Then, they hand-delivered the blankets with a note attached to each one offering words of wisdom for the new mothers.

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Stages of Care

No two people will experience memory loss in exactly the same way. Care needs vary depending on the type and stage of the cognitive impairment as well as the overall health and personality of the individual. Social and environmental factors can also impact the type of care a person needs.

Because memory loss is often progressive, most people will need increasing amounts and different kinds of care as time goes on. While more care will be necessary to keep people safe, the positive approach to care is effective at all stages of the disease. Moments of engagement, without anxiety, are possible for people even as they are in the late stages of memory loss.

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Early-stage Memory Loss

Individuals diagnosed with Alzheimer's or similar dementias can live for many years after the onset of symptoms.ⁱⁱ In the early stages of memory loss, most people can—and should—continue to work, travel, volunteer and learn. Early diagnosis allows individuals to find the assistance they need to live independently and engage meaningfully with their communities for as long as possible.

Family and friends often provide the majority of early-stage memory care. Support groups for both the diagnosed and their caregivers, along with educational resources, can help with the grief that often accompanies a diagnosis.

Some components of care for early-stage memory loss include:

- Engaging the individual as early as possible in planning for his own care, both now and in the future as those care needs change
- Connecting with support groups
- Communicating the diagnosis with friends and family.

Children and care partners should be taught how to emotionally support the person with dementia. For example, people with dementia may struggle with words or concepts. If they mention they're upset that an old friend from college hasn't stopped by

to visit, it may seem illogical if no visit was ever planned. However, loved ones must understand that it's the reality of the person with this disease. The best approach is to validate those feelings of anger or disappointment, and then begin to ask questions about the old college friend, following the trail of those memories.

Family and friends can help their loved ones with everyday tasks such as paying bills, taking medications, planning, organizing and making decisions. They can also help them recall names, faces and events.

The I'm Still Here approach advises against testing the memory of a loved one, with questions such as these: "Look at this wedding picture. Can you tell me who this is?" "Do you remember me?" "Do you know my name?"

Early in the illness, the person living with Alzheimer's grows accustomed to such questions and fears failing the test yet again. A husband who asks his wife this question is likely feeling that she's slipping away, and he's wondering if he still exists in her world. That's understandable. But a better way to engage the person is to give answers rather than ask questions. The husband in this example could show that photo and describe their wedding, helping his wife connect to the sense of joy she felt that day, even if she can't remember the details of the day itself.

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"While cognitive skills may diminish, every person still has the ability to grow and learn."

— John Zeisel, Ph.D., Author

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Middle-stage Memory Loss

During the middle stages of dementia, damage to the brain can make it difficult for people to express thoughts and perform routine tasks. It becomes common for people to jumble their words, have trouble dressing or start acting in unusual ways. They may need more assistance with daily tasks, transportation or performing household chores. Safety and comfort also become more important as memory loss progresses. This may mean acquiring the services of home health care providers or setting up residential care. Employing outside help does not necessarily mean a loss of independence, familiar activities or surroundings.

Care for those with middle-stage memory loss focuses on promoting social engagement and fostering inclusion through group activities. If the person loves going to the opera or ballet, take her to a performance, recognizing that her attention span may be shorter than the performance. Activities like these appeal to the senses and keep the person engaged in activities she enjoys.

Flexibility is key, however. If she decides she doesn't want to attend the performance or decides to leave early, maybe it's an afternoon out for ice cream instead.

Nurturing a successful relationship with an individual with dementia involves being aware of how things one does or says affect that person. Instead of pressing for details, elicit emotions by asking how events and people make her feel. The details of a happy movie she watched in the morning, for example, may not be clear, but she still may recall those positive, joyful feelings when prompted later in the day. Memories haven't disappeared; they may just be locked away. Care partners can help access those memories by mentioning children, grandchildren, vacations or old jobs. While the person with dementia may not start the conversation, the care partner or loved one should be prepared to do so. These are key steps in building relationships and reminding people that who they really are is still intact despite the progression of the disease.

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Even though people with late-stage memory loss may not be able to communicate, they still benefit from engaging with people and maintaining emotional connections with loved ones.

- More than 5 million Americans have Alzheimer's.ⁱ
- 1 in 3 seniors dies with Alzheimer's or another form of dementia.ⁱⁱ
- Alzheimer's disease is the 5th leading cause of death in California.ⁱⁱⁱ

Late-stage Memory Loss

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As memory loss progresses, a person's physical care needs will increase. Deterioration of physical functions—such as swallowing, speaking and walking—may make a person more susceptible to health problems like infections or blood clots. At this stage, people may require 24-hour care.

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Even though people with late-stage memory loss may not be able to communicate, they still benefit from engaging with people and maintaining emotional connections with loved ones. The I'm Still Here approach maintains that playing a favorite piece of music, watching a favorite movie on DVD, looking at art or photographs, and being surrounded by nature stimulate engagement, contentment and empathy.

Some components of care for those with late-stage memory loss include:

- Assisting with walking, eating and dressing
- Providing 24-hour personal care
- Ensuring safety
- Managing pain and end-of-life care

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A key way to offer emotional comfort is through sensory stimulation. If a loved one has always enjoyed the music of Billie Holiday, Louis Armstrong and Frank Sinatra, playing their songs may remind him of joyful times and bring comfort. If the person gets distracted halfway through a song, that's okay. Responding to the cues of the individual is what's most important. Gestures that may seem simple and perfunctory can provide great sensory stimulation. A kiss, hug or other light touch can often convey feelings of love and connection more poignantly than words.

Respecting personhood and upholding dignity for someone living with dementia may require changing the way one perceives and responds to the individual. As cognitive ability decreases and daily functioning becomes more difficult, a caregiver or loved one may unintentionally become dismissive of the person with dementia. Never talk about people as if they're not there when they're present. Instead, include them in the conversation and acknowledge their presence, even if they may not be fully aware of what's happening.

Housing and Service Considerations

People with dementia have a wide variety of housing and memory care options available to them. While some people choose to care for their loved ones at home, several factors should be considered carefully before making a decision.

Medical Conditions

For many people with good underlying health, home care services may be adequate to support personal assistance needs, particularly in the early stage of memory loss. However, coexisting medical conditions, such as heart disease, high blood pressure, osteoarthritis or diabetes, may increase the need for skilled nursing services or a move to an assisted living community.

In a community with memory care specialists on-site, caregivers can assist with tasks that might be too much for the family, such as bathing and eating. Additionally, assisted living communities, such as those offered by Elder Care Alliance, often feature special floor plans with wide, even walkways and other physical structures that promote purposeful wandering, which reduces stress and encourages curiosity. This type of physical environment promotes residents' independence and empowerment.

Environmental Factors

People with memory loss require specific modifications to their environment to live safely and happily. Securing windows and doors, covering electrical outlets, removing extension cords and other trip-and-fall obstacles such as area rugs, and installing guards around heaters to prevent burns can help ensure the safety of some individuals.^{xi} Mobility and balance problems can prevent a person with memory loss from thriving at home, in which case, assisted living may be a good alternative.

In a resident's room, family photos, awards and other personal mementos are often displayed where he or she can see them. There's less stress and anxiety for people when they're surrounded by familiar things and can claim that space as their own.

In shared spaces, each room should have its own distinct personality and clearly defined function. This reduces confusion for a resident and makes it easier for her to know how her behavior should change in shifting environments. If a resident is confused by her surroundings, she's more likely to retreat and isolate herself.

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Elder Care Alliance uses art and discussion groups to stimulate the senses and communicate through the power of stories. Reading and writing poetry inspires creativity and appeals to the senses.

Engagement Services

Staying connected to personal hobbies and social activities allows people with memory loss to live more fulfilled lives. Crafts, music and art therapy, light therapy, pet therapy and reminiscence therapy are all examples of engagement strategies that provide comfort and a sense of purpose for people with memory loss.

Elder Care Alliance and other assisted living communities with memory care neighborhoods have highly skilled staff trained in how to engage residents. But not all assisted living communities are alike. The depth of training and robustness of programming can vary widely. Elder Care Alliance uses art and discussion groups to stimulate the senses and communicate through the power of stories. Reading and writing poetry inspires

creativity and appeals to the senses. In group activities, the leader may pass around a unique or surprising photo. Residents can then create a name and story about the picture—as simple or as elaborate as they choose. The beauty of this type of exercise is that it doesn't require the resident to recall a name or event. Instead, these low-risk activities encourage creative expression, facilitate connection to memories that remain, and are tailored to the stage of memory loss of the resident.

While staff-led activities are part of the story, in Elder Care Alliance memory care neighborhoods, residents lead many of the activities—creating vocational wellness and reinforcing the belief that individuals still have knowledge to contribute and share.

Caregiver Training and Support

To truly understand the needs of this population, caregivers must be adequately trained in memory care techniques to communicate and respond effectively, assisting residents in expressing their wants and needs. “Residents living in memory care communities can be the most vulnerable because they’re dealing with a cognitive disability and often aren’t able to speak or advocate for themselves,” said Main.

Elder Care Alliance, for example, combines specialized training—based on the latest research—with programming techniques designed for memory care. The leadership team in each community supports the memory care neighborhood and includes a memory care director, life enrichment director, spiritual care director and support staff. The team stays up-to-date on the most innovative and effective approaches to memory care, ensuring programming and services reflect these methods.

Several states have implemented mandatory training hours for memory care providers; however, there is currently no

national accrediting body that oversees education, certification and continuing training in this area. Therefore, training and programming can vary widely between memory care providers. At Elder Care Alliance, new memory care employees complete intensive training over several months to learn about the effects of dementia, communication principles, the dining experience and life enrichment programming.

Holistic Wellness

High-quality memory care goes beyond addressing individuals’ physical needs by nurturing the emotional, spiritual, intellectual, vocational, environmental and social needs of the individual.

Not all memory care communities follow such a cohesive approach. Elder Care Alliance has found that when all of the dimensions of wellness are considered, people living with memory loss can live life to the fullest with whatever abilities, memories and interests are present for them at that point in time.

Family members provide 85 percent of the care for older Americans. In 2013, friends and family members provided 17.7 billion hours of unremunerated care for people with Alzheimer’s disease and other dementias.ⁱ



“Dementia isn’t a medical problem. It’s a social problem.”

— John Zeisel, Ph.D.,
Author

The Future of Memory Care

Much of the dementia research and legislative policy focuses on the high societal cost of caring for people with cognitive impairment. These costs are defined as the unremunerated care provided by family members (in terms of loss of productivity at work and any additional need for time off) as well as the medical costs of treatment and long-term care.

According to the Agency for Healthcare and Research Quality, a growing body of research suggests that non-pharmacological, community-based approaches to memory

care can be effective in reducing the behavioral changes associated with memory loss and in lessening the psychological burden on caregivers.^{xii}

“Dementia isn’t a medical problem. It’s a social problem,” said Zeisel. People living with dementia have a lot to offer the world. Focusing on the strengths of the individual and including the person in society without prejudice or shame can help her live in the present, enjoying a life filled with meaning, human connection and worthwhile experiences.

- i. 2014 *Alzheimer's Disease Facts and Figures*, 2014, Alzheimer's Association
- ii. "10 Facts on Dementia," World Health Organization
- iii. "California Alzheimer's Disease Program," California Department of Public Health
- iv. "Dementia," 2008, American Geriatrics Society
- v. "Younger/Early Onset Alzheimer's & Dementia", Alzheimer's Association
- vi. "Parkinson's Disease Dementia," Alzheimer's Association
- vii. "*The Baby Boom Cohort in the United States: 2012 to 2060*," May 2014, U.S. Census Bureau
- viii. "*Behaviors Associated with Dementia*, 2005," *American Journal of Nursing*
- ix. "*Memory Care and Wellness Services: Efficacy of Specialized Dementia Care in Adult Day Services*," March 2014, *The Gerontologist*.
- x. "How Can Montessori Methods Help Alzheimer's Patients?" 2013, *Alzheimers.net*
- xi. "*Home Safety for People with Alzheimer's Disease*," 2010, U.S. Department of Health and Human Services
- xii. "*Non-pharmacologic Interventions for Agitation and Aggression in Dementia*," November 2014, Agency for Healthcare Research and Quality