

‘Thriving with dementia’:

Innovative efforts to support quality of life



A focus on what can be done helps older adults and their families thrive in environments, activities and support

by Sally Abrahms

Older adults are getting even older. Thanks to better health, science and technology, many more people are living into their 80s and 90s.¹ Because advancing age is a risk for dementia (a syndrome that includes symptoms such as memory loss and impaired thinking),² the World Health Organization predicts that people with dementia will triple in number worldwide within three decades—from about 50 million today to 152 million by 2050.² Currently, up to 70% of dementia cases may involve Alzheimer’s disease.² While there is no cure for Alzheimer’s,² senior living pro-

viders, adult day centers, and Alzheimer’s and dementia experts are increasingly approaching the disease (and other dementias) differently.

“Dementia is about thriving, not just surviving” is the new mantra. This shift is all about what people with memory loss *can* do—tapping their assets, encouraging social interaction, stimulating their creativity and making life more meaningful (and fun). It’s about destigmatizing dementia, too.

These ways of thinking are impacting how and where people with dementia live. The spotlight is also on supporting their caregivers.

The timing could not be better. In the United States, 5.8 million people live

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Canbrit Development, developer and majority owner of The Village Langlely, donated a tandem tricycle to the newly opened dementia village in Langlely, British Columbia, Canada. Image courtesy of The Village Langlely



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An older woman enjoys hands-on creative work with students through programming that uses a creative engagement process pioneered by the international nonprofit TimeSlips. Photo: UWM photo services. Image courtesy of TimeSlips

with Alzheimer's alone—that is one person in the country developing the disease every 65 seconds.³ By 2050, three times as many Americans are expected to develop Alzheimer's.^{4,5} In Canada, more than 500,000 people have the disease; by 2031, there will be a 66% increase.⁶

One thing is clear: There is a push to keep people with cognitive impairment in the comfort of their familiar home for as long as possible. And when they no longer can? Many of the newer long-term and memory care communities have the feel of private homes. It is "person-centered" care where, for example, residents are not on a set schedule for waking up and can choose what they want to eat or do. Typically, 10–12 residents live together, each with their own bedroom and bathroom, a shared living room and airy country kitchen. Health-care staff make the meals.

The focus is on making a difference in the lives of people with dementia, helping them to live as well as possible, remain connected to family and com-

munity, and retain their sense of identity longer. From supportive environments to creative programs, innovative efforts—including those below—help individuals thrive as they navigate this life passage.

Local dementia-friendly communities

Because of the surging demographics and more enlightened attitudes, public awareness of dementia is rising. Forty states in the US have "dementia-friendly" cities,^{7,8} towns and counties, as do many countries around the world. This means they are making their communities welcoming to people with dementia and their family or professional caregivers.

This new movement engages a wide professional spectrum including business owners, police officers, bank tellers and college students.^{8,9} Some businesses train staff to communicate with people with dementia, display clear signage in their stores, and offer seating near entrances. They often put a "dementia-friendly" business sticker on their window to show customers that they have this designation.

Dementia-friendly municipalities and counties may have programming such as arts or music activities that people with dementia and their caregivers can attend together. In Brookline, Massachusetts, near Boston, an initiative called It Takes A Village was started with a town grant through ARTZ (Artists for Alzheimer's), a program of The I'm Still Here Foundation.¹⁰ It has brought those with dementia and their caregivers to arts and cultural events in their area.¹¹

Events have included:

- Watching snippets from famous films with a film educator at a 1920s Art Deco movie theater in town
- Attending an interactive storytelling program at a local book store
- Creating art at the town's art school
- Taking part in a performance at its music school
- Visiting an auto museum on park grounds and discussing vintage cars, including their own in the past

Memory cafés have also gained traction. These are comfortable venues where individuals and caregivers can listen to music, watch old movies, play games or simply support one another. Offered in coffee shops, galleries, museums and community centers, memory cafés are another way for caregivers and adults with Alzheimer's to socialize together. For family members, attending is a welcome break from their caregiver/care recipient role, a way to mitigate stress and isolation and to meet others.¹²

A Dutch psychiatrist founded the memory café concept in 1997 as a way to break through the stigma of dementia. The idea spread throughout Europe and now has a global following.¹²

The creative arts

There is also a growing movement to involve older adults—those with dementia and those without—in what is known as the "creative arts."¹³ Rather than

passively watching a play or musical performance, for instance, they actively participate in long-term care and senior center programs.

Facilitators, professional artists, actors, songwriters, storytellers, dancers and chorale directors work with individuals in community and recreation settings. This kind of collaboration and stimulation enhances the older adults' quality of life.

A number of studies,¹⁴ begun as early as 2001 by the late gerontologist Gene Cohen, MD, PhD, show the physical and emotional benefits of participating in the arts and learning something new. Among them are a reduction of pain (less medication), fewer falls, decreased depression and loneliness, better mobility and concentration, and an increased sense of well-being.

More evidence-based research¹⁵ has confirmed the effectiveness of the arts for older adults, many of whom have memory issues. "The major shift has been from doing for, or entertaining in a passive, limited capacity to, 'Let's make something together that is meaningful and build community and relationships,'" says Anne Basting, founder of the international TimeSlips¹⁶ program.

The organization trains staff at long-term care, adult day and senior centers, as well as individual family members, to actively engage with older adults. It might be making up a story together, acting on stage or using sound, visuals, facial expression, movement or words. Basting's program has trained 860 certified facilitators in 48 states and 19 countries, primarily in long-term care.¹⁷

"At our very deepest, human beings need relationships," Basting says. "One of the pains of dementia is increasing isolation by stigma or institutional settings or the disease itself. Our approach teaches care partners how to bring someone with



Created in collaboration with TimeSlips, the play Wendy's Neverland was performed in 2019 (including this March 24 performance) by rural Signature HealthCare communities. Photo: Randy Daniels. Image courtesy of TimeSlips

dementia out into a relationship." She adds, "It's very painful for a care partner to not feel as though the person is there; when you feel it, it makes the care worthwhile."

Signature HealthCare offered the TimeSlips training at 12 rural care communities in Kentucky as part of the three-year I Won't Grow Up project. Starting in January 2018, facilitators worked with each community for a year. Residents, staff and artists wrote, created and collaborated to stage an original interpretation production of the Peter Pan story at four Signature locations in spring 2019.¹⁸ (Year three will see more efforts to train staff with the goal of sustaining the project for the area.)¹⁹

"It completely transformed the care communities," says Basting. "People who hadn't been out of their rooms for six months were participating. Families who had stopping visiting started again. TimeSlips dramatically changes people's perceptions of what is possible in late life."

Other evidence-based arts initiatives for people with dementia and their families include:

- Alzheimer's Poetry Project: poetry in combination with music and dance^{20,21}
- Opening Minds through Art (OMA): intergenerational art-making²²
- KAIROS Alive!: dance and movement (including for those with walkers and wheelchairs)²³
- Dementia choirs: range from The Unforgettables, started by Mary Mittelman, DrPH, a research professor at the New York University School of Medicine, to Together in Song in Cedar Rapids, Iowa. In 2018 alone, more than 10 dementia choirs were formed.²⁴
- Museum programs: interactive gallery discussions and art-making take place at many museums through initiatives such as the ARTZ Museum Program.²⁵ At New York's Museum of Modern Art (MoMA), art educators

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lead the free Meet Me at the MoMA programs that take place monthly on the day the museum is closed.^{26,27,28}

[**Ed.** The MoMA Alzheimer's Project expanded on the museum's education initiatives for people with dementia and their family members or care partners. The project, which ran from 2007 to 2014, created resources for assisted living communities, care organizations, family members and art/museum professionals to use in developing art programs for those with mild through moderate Alzheimer's.²⁹ These resources are available online (see the sidebar on page 32 for MoMA's Meet Me website).]

Dementia villages

Recently, an innovative elder housing model for people with dementia that started in the Netherlands in 2009 has begun to be replicated in other parts of the world, including the US and Canada.

Hogeweyk, a gated community outside Amsterdam, is not "your average nursing home."^{30,31} The village looks like a regular town (grocery store, café, movie theater, post office, town square, gardens) yet 152 people with severe dementia live there. Residents are free to go wherever they want on the grounds. The goal is to create a sense of normalcy. Restaurant workers and store and bank clerks are trained to interact with residents; no money changes hands during store transactions.

Near San Diego, California, is a new adult day center that, too, is more like a village. Glenner Town Square features stores including a pet shop, hair salon, library and museum.³² But it is different from Hogeweyk: No one sleeps there and everything looks like it is out of the 1950s. Because Alzheimer's often means loss of short-term memory, the idea is to trigger associations from the long-ago past (long-term memory) through what is known as "reminiscence therapy." Everything, from the décor to the cars to

the 1950s movies at the theater, evokes a more familiar era, which can give a sense of comfort and security to those with memory loss.

Coming soon is a residential "dementia village" expected to open in 2020 or 2021 as part of the Miami Jewish Health system in Florida. The S. Donald Sussman EmpathiCare Village^{33,34} will have a town square, creative arts center, café, spa and stores. People with memory disorders in the larger community will also be welcome, as will visiting families and young children.

The focus will be on forming caring relationships between residents and families. All employees will be trained in the EmpathiCare model: understanding and working with dementia residents based on empathy. Nurses and aides will not wear uniforms, and medical carts will be discreetly placed.

"It is easy to design a cool place that can look like a village or neighborhood," states Marc Agronin,³⁵ MD, who conceived of the EmpathiCare concept and the village. The geriatric psychiatrist and author, who is senior vice president for behavioral health and chief medical officer, MIND Institute, at Miami Jewish Health, believes "the challenge is what takes place inside. Is it truly a functional community where people with memory disorders are involved in the best caring relationships?"

EmpathiCare Village won't have reminiscence therapy. "It doesn't work in Miami with such a diversity of backgrounds and ethnicities," Agronin says. "There is no way we would find something in common."

The Village Langley in Langley, British Columbia, opened in August 2019.³⁶ At capacity, Canada's first "dementia village" will accommodate 76 residents who live together in six cottage-style households, supported by 72 specially trained staff.

Residents can wander the five-acre secured grounds and visit the animals in the barn, head over to the water gardens or drop by the community center's art area, store or bistro. Common areas draw people and help them connect, whether they live or work in the community or visit friends or family there.

"What we want is to create a space where people can live life to the best of their ability in their own way," says project leader Elroy Jespersen—"...whether they want to go shopping for groceries, meet a friend for a coffee or go and feed the animals. We want them to have the freedom to do so."

Jespersen and his project partners hope that in light of Canada's new National Dementia Strategy—which includes the objective of improving quality of life for people living with dementia and their caregivers³⁷—The Village Langley "will become a new standard of 'dementia living' and be an early pioneer of change" in the country.

Dementia care comes of age

In the next few years, more ways of thinking about cognitive impairment will emerge along with new ways to help individuals with dementia thrive. Richer, more creative environments, engaging programs, greater awareness of the disease and a better understanding of what these older adults are experiencing will improve the quality of life for everyone—older adults, families and professionals.

In the meantime, it is those organizations and communities that know, understand and, when possible, implement the latest research and resources, that are most likely to thrive. And, in the process, they will distinguish themselves. ☺

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Street Journal, TIME, Newsweek, the New York Times, AARP, PBS's Next Avenue, the Boston Globe, Forbes and the Washington Post. *Abrahms also writes for, and consults to, companies focusing on the 50+ demographic. For more information, visit www.sallyabrahms.com.*

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Encouraging empathy

In an effort to understand Alzheimer's disease better, experts are helping healthcare professionals and families experience the challenges of aging and dementia for themselves through what is called "empathy training."

The Massachusetts Institute of Technology's AgeLab has an "empathy suit" that simulates some physical limitations of old age, including those that affect hearing, seeing and walking.^{1,2} Students, designers, architects and others have worn AGNES (Age Gain Now Empathy System) to find out what it is like to use a product or navigate an environment as a 70+-year-old with chronic conditions.¹

At the University of New England's College of Osteopathic Medicine in Maine, students can live in a long-term care environment for up to two weeks through the school's Learning By Living Nursing Home Immersion Project.³ Students might rely on wheelchairs, eat puréed food and undergo regular care for their hypothetical diagnoses. Marilyn R. Gugliucci, MA, PhD, director for geriatrics education and research and the program's creator, has described these experiences as "life-altering" for students, who connect deeply with residents during the immersion. Afterwards, students feel more empathy with older adults and more aware of how to communicate effectively with them.⁴

Embodied Labs' mission is to "activate transformational culture change" by helping caregivers see and care for older adults differently.⁵ The company offers virtual reality (VR) training videos on Alzheimer's and Lewy Body dementia to staff who

work with these older adults in senior services, long-term care, hospitals and academia. VR participants immerse themselves in the different stages of Alzheimer's and follow the life of someone who has the disease.⁶

A three-year research project using the Embodied Labs software is also taking place at the University of New England's osteopathic medical school. In addition to dementia, VR allows students to experience macular degeneration, high-frequency hearing loss and end-of-life conversations personally as a patient.⁷ Empathy increased 95% after students engaged in all three experiences.⁴

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The Village Langley in British Columbia, Canada, features five acres of park-like grounds. Outdoor spaces encourage residents to stay active, with elements that include a barn with animals and a vegetable patch as well as walking trails, activity lawns and sensory and water gardens. Image courtesy of The Village Langley

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Resources

Internet

Alzheimer Society of Canada

<https://alzheimer.ca>

Alzheimer's Association

www.alz.org

Alzheimer's Foundation of America

<https://alzfdn.org>

Alzheimer's Society (United Kingdom): Dementia-friendly communities

[www.alzheimers.org.uk.get-involved/dementia-friendly-communities](http://www.alzheimers.org.uk/get-involved/dementia-friendly-communities)

Anne Basting

www.anne-basting.com

Dementia Australia

www.dementia.org.au

Dementia Friendly America

www.dfamerica.org

Embodied Labs

<https://embodiedlabs.com>

Glenner Town Square

<https://glenner.org/town-square>

Hogeweyk

<https://hogeweyk.dementiavillage.com/en>

The I'm Still Here Foundation: ARTZ Programs and It Takes a Village

www.imstillhere.org

I Won't Grow Up/a TimeSlips Project official Facebook page

www.facebook.com/I-Wont-Grow-Up-a-TimeSlips-Project-1858475507768229

Massachusetts Institute of Technology AgeLab: AGNES (Age Gain Now Empathy System)

<http://agelab.mit.edu/agnes-age-gain-now-empathy-system>

Miami Jewish Health: S. Donald Sussman EmpathiCare Village

<https://www.miamijewishhealth.org/giving/empathicare-donations>

Museum of Modern Art: Meet Me (MoMA Alzheimer's Project)

The MoMA Alzheimer's Project: Making Art Accessible to People with Dementia (resources and research that care organizations and families can use)
www.moma.org/visit/accessibility/meetme

Memory Café Directory

www.memorycafedirectory.com

The Village Langley

www.thevillagelangley.com

TimeSlips, Inc.

<https://timeslips.org>

University of New England College of Osteopathic Medicine: Learning by Living

<https://www.une.edu/com/immersive-experiences/learning-by-living>

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[Ed. Senior Helpers® has launched a franchised Town Square® model developed through a strategic alliance with Glenner Town Square (see page 14 in "Industry news"). For information, see <https://shtownsquare.com.>]