Changes Are (finally) Coming to Memory Care in the United States

When John G. Swanson visited his father in memory care a decade ago, his father repeatedly asked, "Can I go home?" At the time, Swanson was CEO of Willow Valley Communities (WVC), a Pennsylvania continuing care retirement community where his father lived. The experience led him to realize, "a lot of freedoms, autonomy, choice, were removed because of safety," and that for his father, "It just never felt like home."

A few years later, four members of the dementia crisis task force in Sheboygan County, Wisconsin created the nonprofit Dementia Innovations to educate caregivers and professionals, including EMS, law enforcement, and 911 staff, about dementia and how to de-escalate dementia crises. While they saw firsthand how important it was to improve emergency responses, the team came to realize it was a "band-aid" solution. What they really wanted was to prevent the crises from happening.

The leadership of these two organizations came to the same realization: people with dementia needed better environments in which to live. Leaders of two other organizations— Agrace, a Wisconsin-based hospice organization, and United Methodist Communities (UMC), a New Jersey-based continuing care organization— reached the same conclusion. Larry Carlson, the former CEO of UMC explained, "It just wasn't normal…to live with 25 other strangers and it's not normal to live in a locked ward. And it's not normal to say, 'No, you can't go through that door.' And, 'No you can't do this…and no you can't do that.'

In looking for better models of living for people with dementia, the leaders of the four organizations all learned about – and became inspired by— The Hogeweyk, the Dutch dementia village. The Hogeweyk was created in 2009 with the purpose of enabling people with severe dementia to live a normal life. One of the founders, Eloy van Hal, described it in a recent talk as "a neighborhood… where people are sitting outside, where people enjoy nice weather, chatting with each other in front of a fountain, people biking…people dining, family style. It looks like a normal neighborhood in the Netherlands, close to Amsterdam. But what you are looking at is officially licensed as a skilled nursing home."

The Hogeweyk has attracted worldwide attention for focusing on quality of life for people with severe dementia. The World Alzheimer Report 2020 described it as "a paradigm shifter," and news coverage around the world have profiled the village as a model for reimagining life with dementia (link, link, link). In 2016, the first Hogeweyk-inspired dementia village outside the Netherlands opened in Denmark. Since then, dementia villages have opened in ten other countries. A New York Times headline in 2023 stated "As cases soar, 'Dementia Villages' look like the future of home care."

While there have been no academic studies examining the impact of The Hogeweyk, many of the model's core features are positively associated with living well with dementia, including maintaining independence, being socially engaged, participating in meaningful

activities, spending time outside, and living in a small household. Eloy van Hal reports that when people move in, their medications are reduced, on average, from 8 to 4, and that only a handful of the 188 residents are bedridden, and only during the last few days of life. Consistent with this, a recent study of Village Landais, the French Hogeweyk-inspired dementia village, found that residents had substantially shorter hospital stays and were one-third as likely to die in a hospital as a matched comparison group of residents in other nursing homes.

The United States has been slow to create a Hogeweyk-inspired village. For a while it looked like UMC would open the first one in the country. They bought land in 2020, and had architects visit the Hogeweyk and design the village. Former CEO Larry Carlson published a book in 2022 entitled Avendell: Reimagining the Dementia Experience, which concluded: "Hopefully, by the time you're reading this book, we'll be available to show you around in person." However, the combination of community protests against developing the land, which was a historic farm; a lawsuit from a neighboring town; and Carlson's retirement ended the project. In late 2025, UMC sold the land to the local township to preserve it as open space.

The other three nonprofit organizations, though, are moving forward with creating Hogeweyk-inspired dementia villages. Over the past several years, they have all raised funds; consulted with Be Advice, the Hogeweyk's consulting group; and worked through the enormous range of details involved in designing, constructing, and operating the villages. In the span of just more than a year, all three are scheduled to open.

Dementia Innovation's village will be the first to open. Named Livasu- a blend of the words "living as usual"- the village will welcome its first residents in August 2026 in the Town of Wilson, an hour north of Milwaukee, Wisconsin. WVC will follow with the opening of the Marlin and Doris Thomas Memory Center, named in honor of the organization's founder and his wife. The Lancaster, Pennsylvania center is scheduled to open in September 2026, with residents moving in early in 2027. Agrace plans to open the Ellen and Peter Johnson Dementia Village in Fitchburg, Wisconsin, in September 2027. It is named in honor of the Johnsons in recognition of their $7 million donation and history of philanthropic support for Agrace.

The purpose of all three communities is to support residents to live as normal a life as possible, preserving their autonomy and quality of life. Lauren Renehan, the Mission Director of WVC's Memory Center, explained, "People living here will have the choice to live however they'd like to live. We will support them in their daily rhythms, their daily habits, their daily hobbies, whatever brings them joy and purpose and belonging." For residents, this means they can wake up on their own schedule, walk outside their homes when they want to, shop at the village market, and continue the hobbies they have enjoyed for years. At Agrace, for example, residents will be able to use an electric lawnmower. "If a resident wants to mow the lawn, they're going to mow the lawn," said Trish Clary, the executive director of the Dementia Village.

In the three villages there is an acceptance that living a normal life may not always mean making the healthiest choices, because simple pleasures are important in life's last stage. "If you want to have ice cream for breakfast, lunch, and dinner, then go ahead…we're going to support whatever the person wants at that time," explained Lauren Renehan. Similarly, the villages recognize that autonomy requires accepting some level of risk. Mary Pitsch, founder and board chair of Dementia Innovations explained, "Safety at all costs…when we focus only on that, we are only focusing on a dementia diagnosis, and we're not letting the person with dementia be able to live a full life."

Residents will live in home-like neighborhoods in each of the villages, which will all have a restaurant, grocery store, salon, gym, club rooms, and walking paths. In WVC and Agrace's villages, which will both be licensed as assisted living, households will have 10 and 8 residents respectively. Meals will be prepared in the household kitchen, with residents helping out if they wish. Everyone will eat together at a family-style dining room table—unless they choose to eat at the village restaurant. Each resident will have a private bedroom and bathroom, furnished and decorated with their own belongings. At WVC, there will be a few larger rooms that will enable couples, if they both have dementia, to live together.

Following the Hogeweyk model, WVC and Agrace will use a lifestyle assessment to place residents in households based on shared characteristics. Trish Clary explained, "The goal is to have people who are all like-minded, living together in the same household." Agrace will have three types of households: explorers, socializers, and neighbors. WVC will have urban households within the town center, where the restaurants and grocery store are located, and suburban households north and south of the town center.

Dementia Innovation's approach to household living differs from the other two villages. It is, though, consistent with Hogeweyk co-founder Yvonne van Amerongen's hope for the model's future. In a 2013 interview, she said, "We want it to be possible for the partners of our residents to live here too." That will be the reality at Livasu, where residents will own their own homes allowing spouses, other family members, and pets to live with them. The manufactured homes, ranging in price from $95,000-$175,000, have been tailored for people with dementia, with no steps at the entrance and there are wheelchair-accessible showers. Homeowners, as the residents will be known, will be able to purchase care and support at different levels, based on their needs.

There will be 10 neighborhoods at Livasu, each with 10-14 houses around teardrop-shaped green space. Each home will have a front porch designed to serve as an "outdoor room," encouraging interactions among neighbors. There will be a lodge at the top of every two neighborhoods, where people can share meals together, if they prefer not to eat at home or in the village restaurant. One woman, who will soon be moving into Livasu with her husband who has dementia, described the model as "an answer to a prayer." She explained, "I can be with my husband, in my own little house. If we want to see people, we can see people and if we want to be alone, we can just go into our house."

One aspect of the Hogeweyk's model that has received less attention is demedicalizing dementia care. At a recent presentation Eloy van Hal observed, "A lot of medication people use is…not helping to have a good day while living." He highlighted that some medical interventions can leave people spending weeks in the hospital or being bedridden, not enjoying life. As he explained, **"**You have to talk about dying and end of life and accept that. And stop at a certain moment with all kinds of interventions that don't help you to live a good life."

All three villages embrace the idea of reducing medication burden and excessive treatment. "We definitely are taking the approach that if it's not critical to quality of life, then we don't want to continue it," said Lauren Renehan. Providing end of life care is what Agrace, a hospice organization has done for almost 50 years, and the other two villages work with hospice. Trish Clary explained, "We all know that death is a natural thing. It's something that's going to happen to all of us. And people…should pass in their home, comfortable with their family around them and that's what we want to continue that here in the village."

There are several other elements of the Hogeweyk model that all three villages have also embraced. One is welcoming the larger community into the village. The restaurants in each of the villages, for example, will be open to the community. At Livasu, Mary Pitsch explained "[There will be] different opportunities for the public to come in and realize that these are just people like you and me. That's part of breaking down that stigma of what really living with dementia is like."

Another area is the dementia-friendly design. At the Hogeweyk, the neighborhood is designed so that residents are nudged to be physically active. In order to go to the market, restaurant, or club house, they need to walk outside. That will be the same in the three villages, and walking paths will be used to encourage people to walk in certain directions while strategic landscaping, like uncut grass, will discourage going in other directions. Dementia Innovations and WVC's villages are using unique colors and design for each neighborhood so they are easily recognizable.

The leadership of all three villages hope that their efforts will become catalysts for reimaging how people with dementia can live in the United States. Lauren Renehan is already informally coaching an interested group in Texas, sharing "what our experience has been, what the things are that we've learned." Reflecting on the three villages that will be opening in the United States, Eloy van Hal said, "What I hope, and what I expect that will happen is that with… the new models that they will become the example. That there will be more pressure on the CEOs and all the developers to really reinvent the model of care."

Highlighting the importance of changing how people with dementia live is especially timely, as the Department of Health and Human Services is conducting a comprehensive update of the National Plan to Address Alzheimer's Disease in response to the 2024 reauthorization of the National Alzheimer's Project Act. The initial plan, published in 2012,

did not address “quality of life” for people living with dementia at all. Although there was a strategy for improving well-being, the focus was on family caregivers rather than on people living with dementia themselves. Similarly, its long-term care recommendations focused on reducing inappropriate use of antipsychotics—and important goal—but did not address how dramatically the long-term care environments for people with dementia need to be improved.

In contrast, national dementia strategies in countries including Canada, New Zealand, Japan, and the Netherlands explicitly emphasize quality of life for people with dementia. As the United States revises its national strategy, these three dementia villages show what placing a greater emphasis on quality of life can look like—and make clear that as long as there is no cure for Alzheimer’s disease and related dementias, how people live with dementia should be prioritized alongside efforts to prevent and treat the disease in the United States.

Acknowledgements: The authors have no conflicts of interest.