

The Atlantic

Living, and Dying, at Home

America is aging, and most seniors want to stay in the places where they've lived for decades. Can they? What will it take?

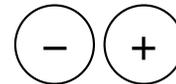


Cathal McNaughton / Reuters

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TEXT SIZE



A few years back, a Domino's pizza delivery worker named Susan Guy began to worry about one of her elderly customers, Jean Wilson, who had ordered a pizza a day for three years. Guy hadn't received an order from Wilson for a few days, so she went to Wilson's house and knocked on the door. When Wilson didn't answer, Guy checked with a neighbor and then called the police, who beat down the door and found that the elderly woman [had fallen](#)

and was unable to reach the phone to call for help. The woman was rushed to the hospital, and survived the ordeal.

The story illustrates one of the biggest fears many seniors and their families face about aging alone. What if something should happen? What if no one is there to help?

To avoid ending up in situations like Wilson's, seniors often move to assisted-living communities and to nursing homes, shepherded there by their worried children. This is a pricey proposition—assisted living costs, on average, **\$3,000 a month**, and some Continuing Care Retirement Communities require seniors to cough up a hefty down payment, say \$250,000, for their apartment (which sometimes is refunded to heirs upon the resident's death).

But the economics of this aren't going to work for much longer. By 2050, one-fifth of the total U.S. population—about 88 million people—**will be 65 and older**. Many of them won't have saved enough money for an assisted living or retirement community. Some low-income seniors may be able to get Medicaid to pay for nursing home costs, but states and local government budgets will have a hard time handling the crunch, and besides, many of the places that take Medicaid are under-staffed and run-down. Many aging people will not find them to their liking.

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These are all reasons why an increasing number of people are saying that seniors should stay at home as they age. This change could save the nation billions of dollars—one study found that the median monthly payment for non-institutional long-term care was \$928 compared to \$5,423 for nursing homes. But shifting seniors to aging at home is going to require a much bigger commitment on the part of everyday Americans—like the Domino’s woman—to pitch in and help their aging neighbors thrive. It’s going to require neighbors to check in on one another all the time; it’s going to require college students to provide care to the aged and infirm; it’s going to require that everyone thinks more about the elderly people around them, and volunteer to take them grocery shopping or shuttle them to a doctor’s appointment. (Yes, including you.)

“Are there strategies that could be used in order for people to stay in their communities for as long as they can and not break the bank? The answer is yes,” said Lawrence Force, the director of the Center on Aging and Policy at Mount Saint Mary College and a proponent of this strategy, told me. “The only thing you have to change is the attitudinal perspective of what kind of supports are out there naturally already.”

* * *

In the late 1990s, as Susan McWhinney-Morse reached age 65, she kept receiving one piece of advice: move. Move from the narrow streets and cobblestones of her Beacon Hill neighborhood, to somewhere warmer, where she wouldn’t have to go through another New England winter, to a spare room in one of her children’s homes, to an assisted living facility or home for seniors.

But she’d lived in Beacon Hill for 50 years, and didn’t want to move, especially not to a CCRC, or Continuing Care Retirement Community, where you progress from independent living to assisted living to nursing

home. You might enter there standing up, but you'll almost definitely leave in a box.

“Why, just because we had turned this mythical age of 65, were we supposed to check our brains someplace else and become passive about our lives?” she asked me. “That still makes me angry when I think about it.”

So she and a group of friends in the neighborhood started to talk. What if they banded together and created a network of like-minded people who were aging, but who knew they didn't want to go to a nursing home? They could help one another when they needed it, recommend plumbers and doctors and home-care aides to each other, and schedule social events so no one would be isolated at home. The network would mean they wouldn't have to be a burden to their children, and they wouldn't have to go to a nursing home, either.

“There was this sense of wanting to be responsible about how we age, wanting to make sure that we had a fallback position ... that we had somebody behind us when we needed help,” said McWhinney-Morse, who is tall, with a shock of white hair and a whiff of New England gentility. “We wanted to create our own future.”

McWhinney-Morse and her friends started discussing Beacon Hill Village, a network of seniors in her dense Boston neighborhood. The Village concept has since been duplicated more than 150 times across the world, and 120 more are [in development](#). On the surface, Villages are simple. They create a network of seniors who live at home, and vet service providers that members might need, such as plumbers, home-care aides, or drivers. The collateral benefit: a network of people who can participate in activities together, go to museums together, and otherwise socialize ([studies](#) have shown that seniors who continue to participate in activities they enjoy fare better than those who don't).

When the founders created Beacon Hill Village in 1999, the idea of encouraging seniors to age at home was not in vogue. This was the heyday of assisted living facilities: In that year, 60 percent of assisted-living facilities had been in business for **fewer than 10 years**, and one-third had been in business for fewer than five. Resisting what seemed, at the time, like the most popular path, was a challenge. But McWhinney-Morse and others knew that living in such communities wasn't how they wanted to spend their retirement.

“I don't want to live surrounded by only people like me ... meaning, old,” McWhinney-Morse told me. “To be greeted by the same unctuous woman in the dining room every night? I would die. Quickly.”



Susan McWhinney-Morse, right, and Tina DiMaggio at home in Beacon Hill (Alana Semuels)

Each Village operates differently. In Beacon Hill, single members pay a fee of \$675 a year, which supports a full-time staff. But other villages are run by volunteers and have much lower fees.

Villages have helped people stay at home for far longer than might have been possible otherwise. When Tina DiMaggio joined Beacon Hill Village, for example, she mostly wanted a social network because many of her friends had died. But then she broke her hip. Her doctor urged her to move into assisted living—his mother had resisted, he told her, and ended up loving it. But DiMaggio didn't want to leave Beacon Hill.

“I'd always decided that I wanted to live alone, live by myself, and take care of myself,” DiMaggio, who is now 92, told me.

When DiMaggio returned home after completing rehab for her hip, she realized her mattress was too high off the floor and she couldn't get into bed. She called Beacon Hill Village, which spread the word to its members, and within half an hour, four volunteers came forward to help DiMaggio move her mattress to the floor.

Of course, people have to have a lot of money to live in Beacon Hill, and for some seniors, the \$675 fee would be a deal-breaker. But some villages don't charge a fee at all. Ninety miles east of Beacon Hill, a man named Dick Elkin and his wife Esther started Nauset Neighbors, a Village for people living on the tip of Cape Cod. They charge members only \$75 a year, and they waive the fee for anyone who can't pay. To keep costs low, the Elkins decided to seek out an abundant local resource: volunteers. People move to the Cape to retire, and are often relatively young and looking for a network of friends and something to do, Elkin told me. The Elkins set up an online database that allows volunteers, whose average age is 68, to sign up to drive Village members to the doctor or to go grocery shopping or to just sit together.

Nauset Neighbors now has about 320 volunteers, and 80 percent of the services they offer are rides to the doctor, the grocery store, or a community event. The Village has no paid staff, but serves 260 members, with an

average age of 84. While some have moved into nursing homes as they've aged, some have died at home, Elkin said.

“You ask anybody and they would much rather stay in their home for as long as possible—it's their comfort zone,” he said. “They'd rather stay home and do nothing than be with other people in assisted living.”

Nauset Neighbors is the type of network that some advocates think will need to be replicated as more Americans age.

“There's going to be more demand for different ways of thinking about service delivery,” said Robyn Stone, the executive director of the LeadingAge Center for Applied Research, which looks for ways to improve the lives of older Americans. “That means the use of new kinds of kinship relationships, more dependency on friends and neighbors and not just family.”

A few such communities already exist. An effort called the [Caring Collaborative](#), launched in 2009, seeks to “organize the goodwill” that exists in informal communities in places such as New York City and San Francisco to help women as they age. The [National Shared Housing Resource Center](#) brings together seniors who have housing with housemates looking for a place to live. And Naturally Occurring Retirement Communities (NORCs) in places such as New York City allow seniors to stay in their apartments and have services brought to them.

These communities mostly exist in cities so far, which raises the question of what will happen to seniors who live in rural or suburban areas, who might be very isolated should they try to stay at home. But Lawrence Force, of the Center on Aging and Policy, said that could be an incentive to encourage more people to move back to housing in urban settings, so they can age there, rather than in an institutional setting.

"This basically is a place where people can live and get services coordinated with health care and can remain there until they die," she said. "It's less costly and it's also a much better quality-of-life for these folks."

He envisions what he calls Naturally Occurring Living Communities, which require people thinking differently about staying at home. Perhaps this means creating high-density housing for seniors on college campuses, where students come to check in on seniors (one Dutch nursing home already offers [rent-free housing](#) to university students if they spend 30 hours a month acting as “good neighbors”). Perhaps it means creating housing for low-income people in seniors’ homes, or encouraging everybody to behave like the Domino’s delivery woman, and check in on the seniors in their lives. Force compares the strategy to going into a theater and putting on a pair of 3-D glasses, “and seeing connections you never saw before.”

“There are other supports that can be dug up, that can be brought to the table, as a way of helping the individuals stay where they are,” Force told me.

* * *

Some people may not be able to stay in their homes despite helpful friends and neighbors. Their property taxes may be too high, or they may have to sell their homes in order to finance long-term care. Because of the housing crisis, their houses may not be as much of an asset as were the homes of the previous generation.

“We talk about equality, but things aren’t equal,” Force told me. “If you knock on the door of a Village with a thin wallet, you’re not going in.”

Aging is [more difficult](#) for low-income seniors, especially because there’s

been little to no growth in affordable senior housing, Stone said, even as the senior population continues to grow. Some seniors will be forced to forgo essentials such as food and healthcare in order to spend money on housing.

“We believe very strongly there’s going to be a housing crisis and a residential-options crisis for a burgeoning elderly population,” Stone told me.

Many low-income people end up on Medicaid, so it makes sense to find ways for them to live at home, rather than move into a nursing home on the government's dime. One 2005 survey indicated that more than 160,000 nursing-home residents would prefer to return to their communities and receive Medicaid waivers, which could [save the government](#) \$2.6 billion.

Helping seniors age at home can save Medicaid anywhere from \$22,588 to \$49,078 annually, according to the [Center for Housing Policy](#). That’s even though, in some cases, seniors who aged at home received housing subsidies or government vouchers.

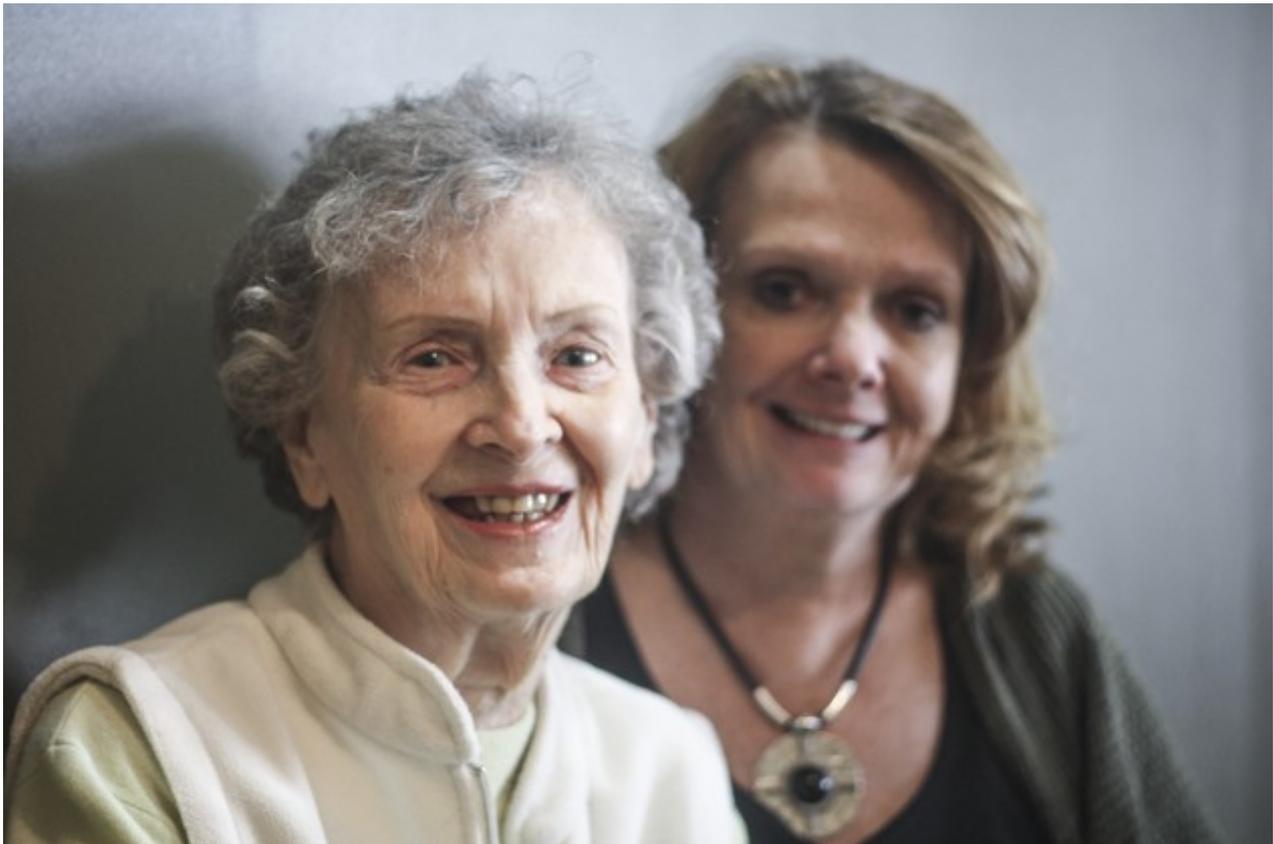
But all too often, when low-income seniors become sick, or go to the hospital, their doctors tell them they can’t live at home anymore, especially if they don’t have the financial or community resources to help them do so. Their only option is usually a nursing home, since they can't afford assisted living.

But LeadingAge is working with Congress and HUD on a way to create better options for low-income seniors. It launched a new center, Center for Housing Plus Services, which seeks to find ways for seniors of all incomes to age in place. LeadingAge is working with agencies in Baltimore, Harrisburg, and Portland that have brought medical and other services into publicly-subsidized housing complexes so that residents don't have to move. Many of these senior apartment complexes were not designed to deliver services to residents, but Stone says some of them are beginning to change their thinking to help their tenants.

"It's important for low-income people—why shouldn't they have the same options that a wealthy person has, who move to a continuing care retirement community?" said Stone, who works for the research side of LeadingAge. "It's really a societal question."

One housing development in the Boston area has pioneered this effort to provide more services as residents age, so they won't have to move to nursing homes. Sometimes executive director Jacquie Carson even moves people from nursing homes to the building she runs, Sanborn Place, Home Care and Day Services, in Reading, Mass.

Sanborn Place was, for a long time, a low-income housing complex for seniors and people with disabilities built with the HUD 202 program, which was a tool for expanding the supply of affordable housing for seniors (the program no longer exists). As residents aged, though, executive director Carson started trying to find ways to provide them with more and more supports so they wouldn't have to move to nursing homes.



Jacquie Carson, right, and Sanborn Place resident Virginia Holmes, 87 (Alana Semuels)

At first, some residents were no longer able to cook for themselves, so Carson would arrange for someone to bake casseroles for them, and a group of residents would dine together. That evolved into a meal program that served food to seniors in a common area. Then residents needed help around their apartments, so Carson brought in aides to do laundry and clean their homes. When one resident was diagnosed with Alzheimers in 1998, his family decided they would pay for overnight staff, and the building soon had round-the-clock care.

“The program grew out of people’s needs in the building,” said Carson, who has worked at Sanborn Place for 19 years.

Carson took me on a tour of Sanborn Place, and at first, it was hard to discern what made it different from a traditional assisted-living facility. There were a lot of elderly people milling about, a nurses' station where people came to take their medications, and a lunch service with a somewhat sad-looking cafeteria. There was even a adult day-care room for people who live elsewhere but need assistance during the day, some of whom were severely disabled.

But the difference, Carson told me, is that the people living in Sanborn Place make their own decisions, just as Susan McWhinney-Morse or Tina DiMaggio do. They decide what kind of medical treatment they want, eat their own food, and sleep and wake when they want to. Many of them can leave the apartments and go to the Dunkin' Donuts down the road, or they can stay in their room all day and knit if they so desire. Each resident has his or her own apartment as well, another difference from a nursing home, which has two or three people to a room.

There’s still a lot of room for independence at Sanborn Place, according to

resident Marjorie Hery, 87, who decided to move out of her home in Ossipee, New Hampshire at the urging of her nine children. They were worried about her living alone, and it was getting expensive for her to stay there anyway: In the last year in her home, fuel was \$2,600 alone. She moved into a different HUD senior housing facility in the Boston area, which she said was fine, but “all the floors were linoleum everywhere, and there were nine floors and one nurse.”

Hery got in off the waiting list of Sanborn Place after four years. She now cooks for herself, and spends part of each morning socializing with other residents in the library of the apartment building. It’s not *that* different from assisted living, she told me, except that she can afford it.

“If we could afford it, we’d probably be there, but it’s very expensive,” she told me. “I know they wouldn’t accept me because I don’t have enough money to last that length of time.”

Currently, 35 units of Sanborn Place are set aside for people who need at least an hour of intensive care a day, 25 for people needing scheduled care, and 13 for people who, like Hery, need no assistance at all. People have died in Sanborn Place, with the assistance of hospice care that has come into their apartments. They’ve also continued to live rich lives there; half of the building’s residents have lived there for more than 20 years.



A worker arrives at Sanborn Place, in Reading, Mass. (Alana Semuels)

Even those who need fairly intensive care live independently in a place that feels, to them, like home. I visited the home of Priscilla Carter, 85, who is in a wheelchair and has Parkinson's disease. She had been in a nursing home, but Carson, who does this sort of thing all the time, had pulled her out and set her up at Sanborn Place three years ago. Now, Carter lives in a one-bedroom apartment with a front door that opens and closes, and where the things that are most important to her are on the walls, including her husband's diploma, a few poems she enjoys, and a china set she's had for decades. She can sit on the couch she'd put in storage when she went to the nursing home, and flip through the photo album there wasn't room for before.

Carter veered between being coherent and not; when I asked her how long she'd lived in Sanborn Place, she told me a year, but Carson corrected her.

"You've been here three years," she said gently.

But Carter was aware of her own limitations.

“I was a teacher for 14 years, and I’m very proud of that,” she said. “But all of a sudden you have Parkinson’s and you become totally embarrassing.”

Carson was able to change the dialogue about Carter and people like her, by helping them age with dignity. She talks about visiting a nursing home, and hearing staff refer to a patient by saying that she "used to be a mother." In some institutions, residents become patients, rather than mature people who have lived full lives: That's why Carson is trying to help her residents to continue to be who they always were, just a little bit older.

She used to spend a lot of time arguing with doctors and family members who didn’t believe some of her residents could continue to live in an apartment, alone. She’s convinced some now, by showing them it could be done. One woman, who needed 24-hour assistance available, loved going out to dinner, so staff would put a few Depends on her, and help her go. One woman has been on dialysis for years, but doesn't want to pull the plug until she's ready—a decision Carson is comfortable allowing her to make.

“The people that live here know they’re welcome to pass here,” she told me. “This is their home, this is their family, their friends, their caregivers.”

The nation needs to experiment with more options like Sanborn Place, said Stone, of LeadingAge.

"This basically is a place where people can live and get services coordinated with health care and can remain there until they die," she said. "It's less costly and it's also a much better quality-of-life for these folks."

* * *

Of course, even the most independent seniors will run into problems staying

at home eventually. Perhaps they stop driving and can't get to the store, or they become forgetful and lose their keys, or they get sick and don't have someone who can care for them round-the-clock. Medical advances have allowed people to live longer and longer, but there may be a point when someone can't live alone anymore without expensive 24-hour care.

For two weeks this winter, for example, Susan McWhinney-Morse got extremely sick, and she didn't have anyone to help her. She admits it was "very difficult," and that after the experience, her children urged her to move into a more supportive environment.

"Staying independent is what people want—over and above safety."

But her takeaway from this winter isn't that it's time to move into assisted living. Rather, it's that she should ask for help more frequently. She'd made sure that the help existed, after all, by helping to found the Village. She just needed to change her mindset to admit that she needed it.

Still, I had to wonder, is there a time when even asking for help won't be enough? If elders' families can't care for them during their toughest times, can we really expect strangers to do so? And even if we can, what happens when people don't even know they need help? Do Villages perhaps allow seniors to live a little *too* dangerously?

The stove in Priscilla Carter's apartment, for example, doesn't have any gas, because Sanborn Place decided that it wasn't a good idea to allow people with memory problems to operate gas stoves. But people who live in their own homes won't likely disable their gas as they age, and may not know when to ask for help, even if they need it.

Some of the Villages have started to address this issue: Beacon Hill Village is talking about creating a “permission slip,” of sorts, that members sign, that says that if an individual begins acting hazy or if friends think he or she might be unsafe at home, the Village should communicate this to the individual and their family. Nauset Neighbors modified its membership agreement so that members give the organization permission to talk to local Elder Services if they’re concerned about a member’s stability. And when residents of Sanborn Place forget their keys too many times, or start acting too forgetful, their neighbors or staff will stop them from going out alone. But they can go, with a friend, if they want, Carson said.

“We keep people’s integrity safe, and we look out for each other,” she said.

For now, these safeguards could be enough. They're enough if we decide that aging isn't about prolonging life for as long as possible, but about letting people choose how they live and die. It may be scary to think of mom falling and not being able to get up, but maybe it's less scary if you know she knows she'd prefer that to dreary years of a safe but regimented existence.

As Dick Elkin put it to me, "Staying independent is what people want—over and above safety."

The hope, of course, is that with programs like Villages and Sanborn place, they can have both.

ABOUT THE AUTHOR



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