How Not to Grow Old in America

By June 7, 2019

Assisted living seems like the solution to everyone's <u>worries about old age</u>. It's built on the dream that we can grow old while being self-reliant and live that way until we die. That all you need is a tiny bit of help. That you would never want to be warehoused in a nursing home with round-the-clock caregivers. This is a powerful concept in a country built on independence and self-reliance.

The problem is that for most of us, it's a lie. And we are all complicit in keeping it alive.

The assisted living industry, for one, has a financial interest in sustaining a belief in this old-age nirvana. Originally designed for people who were mostly independent, assisted living facilities have nearly tripled in number in the past 20 years to about 30,000 today. It's a lucrative business: Investors in these facilities have enjoyed annual returns of nearly 15 percent over the past five years — higher than for hotels, office, retail and apartments, according to the National Investment Center for Seniors Housing and Care.

The children of seniors need to believe it, too. Many are working full time while also raising a family. Adding the care of elderly parents would be a crushing burden.

I know this fantasy well. When my parents, who were then in their 70s, were unable to take care of themselves, I bought an apartment in Brooklyn that was big enough to fit them, in addition to my husband and our two young children. But then my husband lost his job in the Great Recession, and we could no longer afford the mortgage.

The only solution I could think of was to move. I took a job in India, where the dollar goes farther, so I could rent an apartment big enough to fit us all and hire helpers to care for my parents and children while my husband and I worked.

Back then, I, too, dreamed about those assisted living facilities. My parents seemed so bored and lonely in my house. And it was hard for us to keep up with their ballooning needs. They grew so enormous that I eventually had to quit my job.

As I struggled to support my parents, assisted living became a private dream for my own old age.

Now that I am back in the United States, I have been thinking about assisted living again. My dad died in 2017, after living with us for nine years, and my 83-year-old mother now lives in New York City with my sister. Would assisted living offer our mother better care and relieve the pressure on my sister, who works full time while raising a young daughter?

Sadly, I've discovered the answer is no.

The irony of assisted living is, it's great if you don't need too much assistance. If you don't, the social life, the spalike facilities, the myriad activities and the extensive menus might make assisted living the right choice. But if you have trouble walking or using the bathroom, or have dementia and sometimes wander off, assisting living facilities aren't the answer, no matter how desperately we wish they were.

"They put their money into the physical plant. It's gorgeous," said Cristina Flores, a former home health care nurse who has a Ph.D. in nursing health policy, lectures in the gerontology program at San Francisco State University and runs three small group homes for the elderly.

But when it comes to direct care, the facilities are often lacking. "The way they market everything is, it's all about autonomy and independence, which are important concepts," she said. Families and residents don't realize that these facilities are not designed to provide more than minimal help and monitoring. Even those that advertise "24-hour" monitoring may have someone present round-the-clock on the premises, but may not have sufficient staff to actually monitor and assist the large number of residents.

"People's defense against something horrible happening is, 'Well, they have a right to be independent," she said. "'Yes, he did walk up the stairs with his walker and fall down and die, but he had a right to do that.' That's a horrible defense. You don't just allow people to do unsafe things."

Most residents of assisted living need substantially more care than they are getting. Half of those residing in assisted living facilities in the United States are over the age of 85, the Centers for Disease Control reports. And this trend is accelerating. The number of people <u>85 years of age and older</u> in the United States will nearly triple to about 18 million by 2050, according to the Census Bureau.

"When you say nursing home, people say, 'Yuk,'" said Eric Carlson, the directing attorney for Justice in Aging, a national advocacy group for low-income older Americans. "When you say assisted living, a lot of people say, 'That sounds good.' Nobody realizes the system is broken." When something bad happens to a resident of an assisted living facility, "They just think it was that facility that was horrible," he says.

Part of the problem is a lack of regulation. Nursing homes are regulated and inspected and graded for quality to ensure that residents receive adequate care. The federal government does not license or oversee <u>assisted living facilities</u>, and states set minimal rules. Nursing homes are required to have medical directors on staff who review patient medications regularly, while there is usually no such requirement in assisted living.

Not surprisingly, complaints against assisted living facilities are mounting in courts around the country.

In June of last year, Claude Eugene Rogers, an 83-year-old retired Marine, suffered from heatstroke at an assisted living facility in Roseville, near Sacramento. He died a few days later. A state investigation said that he had been left on an outside patio in his wheelchair for one hour and 45 minutes or longer that morning, when local temperatures reached 93 degrees Fahrenheit. The state in July moved to revoke the facility's license to operate, which it is fighting to retain, while denying any wrongdoing.

His family was devastated. They had chosen assisted living when his dementia grew more severe and his wife was no longer able to care for him at home. "We thought it was a nice place and the people there could provide great care and the other residents there would be friends for my dad," his son, Jeffrey Rogers, told me.

Bonnie Walker, 90, who also suffered from dementia, wandered undetected out of an assisted living facility in South Carolina sometime after midnight in July 2016. According to a lawsuit, her remains were found eight hours later in a pond nearby, and her pacemaker was recovered from inside an alligator that lived on the property.

At a pond near an assisted living facility in South Carolina, a resident, Bonnie Walker, was found dead after an apparent alligator attack in 2016. Leigh Webber for Kaiser Health News

Stephanie Weaver holds a photo of Bonnie Walker, her grandmother, who suffered from dementia. Leigh Webber for Kaiser Health News

Her family, after struggling to care for her at home, had taken her to assisted living believing she would be safer. They visited her daily and took her home on Sundays. "My grandma deserved to have us there" when she died, her granddaughter, Stephanie Weaver, told me, "not to go the way she did."

Ruth Gamba, 96, fell three times during her first month in a memory care unit of an assisted living facility in Fremont, Calif., her family said in a lawsuit against the facility. Memory care units are supposed to provide closer monitoring and care of patients with dementia. But in Mrs. Gamba's most recent fall, she broke her hip and fractured her toes, her family said in the lawsuit.

Her son, Peter Gamba, a television editor in Los Angeles, told me that he and his sister moved their mother into the facility because it promised round-the-clock monitoring. More than 40 percent of people in assisted living have some form of dementia. Construction of memory care units in assisted living facilities is the fastest-growing segment of senior care. But assisted living, even memory care units, often aren't the right place for people with dementia. In most states, there's no requirement that these units be staffed with enough people or that they be properly trained.

Assisted living has a role to play for the fittest among the elderly, as was its original intent. But if it is to be a long-term solution for seniors who need substantial care, then it needs serious reform, including requirements for higher staffing levels and substantial training.

That will raise prices, and assisted living already costs between about \$4,800, on average, each month, and nearly \$6,500 if dementia care is needed, according to the National Investment Center, a group that analyzes senior housing reports.

Perhaps the United States can learn from Japan, which is a few decades ahead of us in grappling with how to care for its rapidly aging population. Japan created a national long-term-care insurance system that is mandatory. It is partly funded by the government but also by payroll taxes and additional insurance premiums charged to people age 40 and older. It is a family-based, community-based system, where the most popular services are heavily subsidized home help and adult day care. Japanese families still use nursing homes and assisted living facilities, but the emphasis is on

supporting the elder population at home.

We need to let go of the ideal of being self-sufficient until death. Just as we don't demand that our toddlers be self-reliant, Americans need to allow the reality of ourselves as dependent in our old age to percolate into our psyches and our nation's social policies. Unless we face up to the reality of the needs of our aging population, the longevity we as a society have gained is going to be lived out miserably.

As Mr. Gamba told me, "There's going to be lots and lots of old people dying left and right with nobody attending to them."

And there's a pretty good chance, I believe, that among those languishing there will be you and me.

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