

Older Americans often don't prepare for long-term care, from costs to location to emotional toll

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Nancy Gag Braun points to a small urn holding the ashes of her late husband Steve Braun, in her Mankato, Minn., bedroom on May 13, 2024. After caring for Steven at home became too much for her to handle, he was at the hospital while they waited on a long-term care placement. “I cried many nights,” Braun said. “I felt so guilty.” Credit: Casey Ek/CNHI News via AP

Seven tough weeks passed with her husband in the hospital before Nancy Gag Braun found long-term care for him.

From 2019 up until that point in 2022, Braun had cared for Steven at their Mankato home. A traumatic brain injury in February 2019, followed by his progressive dementia, eventually led to the need for professional help and the hospital stay.

By then, there were episodes when he didn't recognize that the woman trying to care for him was his wife. He started showing fear and aggression toward this person he thought was a stranger in his home.

"I knew that wasn't him; it was the disease," Braun said. "It was very sad that he had to go through all this."

Not knowing where to turn, she began calling long-term care facilities, one after another. But his advanced condition made it difficult to secure a spot. She eventually got him in at BridgeWater, a skilled nursing, memory care and assisted living facility in Janesville.

While she's grateful for the care he received there, it wasn't the long-term stay she expected. Steven died at the age of 78 on Nov. 23, 2022, six weeks after coming to the facility.

But Braun's scramble to find long-term care for a loved one is an experience shared by many families. And many of them are unprepared for what can be an emotional, costly and guilt-inducing process.

Advance planning helps, but an AP-NORC poll in 2021 showed most Americans don't discuss the possibility of long-term care, let alone prepare for it.

Braun, a retired county worker, was aware of select resources for people

in her situation and had some savings to go toward this care. Still, during that fraught time, she said she wishes there had been more help available.

"I don't think there's enough information out there for people so they do know," she said.

Where to turn

The resources Braun found helpful included a social worker at her health care provider, Mankato Clinic, who put her in touch with the Minnesota Senior LinkAge Line. The statewide service connects seniors to local resources, including long-term care facilities.

Finding the right long-term care option, in many cases, comes down to who has an open slot and can accommodate a particular person's needs. As Braun found out, not many places would take her husband because of his complex behavioral condition.

Data at the state and federal levels can guide families toward one facility over another. Minnesota's nursing home report-card system, for example, lists star ratings searchable by location. Want to know how the last state inspection went? What families said in recent surveys? How many single-bed rooms a facility has? Check the report cards.

Staff retention, temp-staff usage and hours of direct care are factored in as well. People should consider other sources, the site advises, along with visiting a facility and discussing specific needs with staff.

Nationally, the Centers for Medicare & Medicaid Services maintains a five-star quality rating system. Here, consumers can find ratings based on health inspections, staffing and quality measures by location.

Companies offer similar services to help people search for the right fit. One site, A Place for Mom, uses a mix of residents, resident families and industry experts to rate facilities on a variety of metrics.

Long-term care insurance

John Landas' hunt for long-term care for his parents started with an online search. From there, he visited facilities, sought information from friends and used his intuition to inform the choice that he and his parents made.

Jake and Joan Landas moved from what had been their West Mankato home since 1970 to New Perspective Senior Living about two years ago. She had lost her vision by then and he was dealing with dementia, qualifying them for insurance benefits covering much of their care. Their son is an insurance agent and he helped them set it up.

Paying the insurance premiums for 25 years quickly proved worth it once they needed long-term care.

For John, their only child, it removed a burden from what was otherwise an emotional time.

"It was a huge blessing to have that financial strain not being salt in the wound," he said.

His father paid about \$3,500 per year in premiums starting at age 60 through 85, adding up to about \$87,000 total. It took nine months in long-term care to break even, Landas said, and he's been receiving long-term care now for more than two years. His mother paid similar amounts in premiums and broke even as well before her death on March 23.

They bought "unlimited benefit period" policies, meaning benefits for

long-term care would be provided to them until death as long as they had qualifying conditions. These plans aren't offered anymore, Landas said, with providers instead doing hybrid plans covering long-term care costs over a certain number of years.

Premium costs may seem high, he said, until you need to pay for long-term care.

"Compared to nothing, long-term insurance is expensive," he said.

"Compared to pulling out the checkbook and paying for long-term care, it's not."

Being prepared and making the right decision doesn't mean seeing your parents age is any less taxing, he added.

"I've said a thousand times, they don't prepare you for this," he said.

"I've lost my mom. She passed away a month ago. My dad has dementia. Until you've lost a loved one, a parent, you don't realize how hard it is."

The move was the right call for them, though. His parents' home would've made it unsafe for them to remain there.

Both Braun, as a wife, and Landas, as a son, were able to play the roles of advocates for their loved ones.

Landas talked about being at the facility regularly to build relationships with staff in an industry where the turnover can be high. His wife would bring baked goods to show appreciation for staff members, recognizing the care they give their loved ones.

Balancing guilt

In Braun's case, she kept pushing for a place for her husband even as few

places seemed willing to take him. Limited space at geriatric psychiatric facilities in Minnesota brought her attention to a facility in North Dakota, but she ruled it out because of the distance.

Even if long-term care seems like the logical choice, the decision can still elicit feelings of guilt, as Braun learned. After caring for Steven at home became too much for her to handle, he was at the hospital while they waited on a long-term care placement.

"I cried many nights," Braun said. "I felt so guilty."

She visited him at the hospital one day and, while she was leaving, he kept trying to follow her home. Nurses held him back as her elevator doors closed. Tears poured out as she sat in the car.

Steven may have already been dealing with dementia, but the traumatic brain injury from a fall on ice in front of their home triggered the start of a marked decline. One minute he seemed fine, the next he couldn't do the most straightforward of tasks.

During one of his good episodes, Braun remembers him saying he should've just died when he fell because it would've been easier than what the two were going through.

"He hated what was happening to him," Braun said.

She thinks about how unfair it was for a man who had such a thirst for knowledge to lose so many pieces of himself in those final years. Steven earned a master's degree in biology before teaching classes at Minnesota State University. He took pride in teaching himself calligraphy and was an avid reader, photographer and loved to listen to jazz music.

Braun cried while reminiscing about this Steven. At the home they long

shared, she has a teddy bear sitting in his favorite spot on the couch as a remembrance of him.

As rough as those final years were, and those final weeks looking for long-term care, Braun said she cherished having as much time together with him as they did.

At least the time he had left allowed them to celebrate their 30th wedding anniversary at BridgeWater on Nov. 6, 2022, just 17 days before he died.

For Braun, reaching that milestone was meaningful.

"I kept telling him how happy I was and how excited I was that we made 30 years," she said. "I just kept letting him know that so he'd know."

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