

The high cost of AGING IN THE U.S.

Betsy Winkler has a tight budget to pay for husband David's Alzheimer's care. The couple collect \$51,600 in retirement and other income, but care fees take \$48,000. When David's disease worsens, care costs could rise to \$63,600.

Betsy Winkler's first stop is the bakery counter. It is early on a drizzly summer morning, and the grocery store is neat and quiet. But when the sleepy clerks roll out carts brimming with past-their-prime breads and pastries, the 60-year-old gets to work.

She fills the back of her dusty green minivan, neatly stacking croissants and chocolate muffins, cookies and cinnamon rolls, Dutch apple pie and foot-long hot dog rolls. In an hour or so, the volunteer will deliver the baked goods to the Kuna Good Neighbors Inc. food bank.

Before that, though, Winkler has another stop to make: the grocery store dumpster. That's where she gathers the fruit and vegetables that will sustain her throughout the week. What she does not eat she will can, freeze or dry for even leaner times.

Winkler's husband, David, has Alzheimer's disease. She can no longer care for the 69-year-old in the converted garage she calls home. Every month, Winkler now writes a hefty check to pay for her husband's assisted living facility. And when it comes to her own needs and wants, Winkler makes do.

After she's paid the bills, she tries to live on just \$30 a month. While \$1 a day doesn't go very far, Winkler knows she needs to have something in savings to pay for the increased cost of David's care as his condition worsens.

The Winklers represent the intersection of two Gem State demographic trends. Idaho's population is graying faster than the nation as a whole. And more than a third of the state's households have difficulty making ends meet each month, left behind by a booming economy with its help-wanted signs and soaring construction cranes.

Which is why Winkler is pushing aside boxes of corn husks and watermelon rinds in search of summer's bounty in a grocery store's garbage.

"There's peppers, asparagus, lettuce. Here's a whole bag of potatoes and some apples," she says, head down, intent. "They're starting to get bad, so they toss them out. But there's some nice potatoes. See? It's just not up to their quality. ...

"I've been gathering up mushrooms lately," she continues. "I probably have enough to last me through the winter. Any other mushrooms I get, they just go direct to the food bank. I'm not gonna be greedy about it."

She opens up an ear of corn before filling up her back seat. There is more than enough for her and her struggling neighbors.

“There might be a bug in the top,” she says. “You cut it off!”

At the food bank — a collection of coolers, cupboards and open shelves in the carport of a private home — no one notices blemishes or expiration dates. They are grateful for the groceries. Period.

Keith Hartmann, who had a stroke two years ago and cannot work, drives up in his white pickup truck as Winkler unloads her van. The 57-year-old is especially glad for the mostly fresh produce Winkler has delivered, because he’s been trying to drop a few pounds.

“I try to eat healthy,” he says. “And it’s expensive. ... We’re on a fixed income. When we go shopping, it’s like, ‘We can’t get this. We’re on a budget.’ Before it was, ‘You can never spend too much on food.’ This is a blessing.”

Wrestling with the high cost of care

The statistics are sobering.

The median cost of a private room in an Idaho assisted living facility was \$38,400 per year in 2016, the most recent figure available. A similar room in a nursing home, according to Genworth Financial, was \$88,878 each year. The median household income in Idaho is \$51,624, according to Federal Reserve Bank figures for 2015.

The Winklers earn around \$51,600 each year, mostly from pensions and Social Security.

In other words, the couple would be solidly middle income — if it weren’t for David’s diagnosis.

David’s care at the assisted living facility currently costs an annual \$48,000. When his Alzheimer’s disease worsens, that price tag could rise to \$63,600.

David spent two decades in the Air Force and another two decades teaching incarcerated boys at the Juvenile Correction Center in Nampa. He gets Social Security, a state pension, a military pension and around \$200 a month for a service-related disability.

At 60, Winkler is too young to tap Social Security. She ran a bustling sewing and embroidery business from the same garage where she now lives, making custom patches and repairing leather gear for bikers from around the country.

But she had to sell her business at a loss so she could care for David after he was diagnosed, after he was forced to retire, lost his driver’s license, began to wander and would wake up at 3 a.m. to get dressed and ready for the job he no longer held.

They used to have plans, Winkler said. They wanted to travel. He'd lived in Hawaii as a child and had hoped to show her the state he so loved. Now, she said, that will never happen. The closest she's been to the 50th state was when her older sister visited there earlier this year.

"I splurged," she said. "I gave my sister \$50. And I said, 'Would you please find me a couple of pieces of material so I can make my grandbabies some clothes from Hawaii?'"

This is budgeting, Betsy Winkler style:

What comes in: David gets \$4,300 each month from his two pensions, his small disability payment and Social Security. The U.S. Department of Veterans Affairs gives him \$1,640 each month through a program called Aid and Attendance to help defray the cost of assisted living. Total in: around \$5,940 each month.

What goes out: Aid and Attendance comes with strings. Winkler cannot work, she says. If her income goes up, that benefit will go down. To receive it, David loses his \$200 or so disability payment. Ashley Manor costs \$4,000 each month. The couple's other bills come to around \$1,000. Total out: around \$5,200.

What's left for Winkler each month: about \$740.

But she tries to spend no more than \$30, about half of which goes straight into her gas tank.

Winkler lives on 5 acres in Kuna, with her daughter, son-in-law and two granddaughters. It is the farm she and David used to run when they were able. There are chickens for eggs, lambs for meat, a garden for produce to augment the dumpster.

That allows her to sock away around \$710 each month for that awful day when David hits Stage 7 Alzheimer's disease, when the cost of his care rises from \$4,000 to \$5,300 a month and she can no longer pay the bills or save for his future or her own.

"When his bill goes up to \$5,300, where's that money going to come from?" she asks. "So I'm doing my best to live as minimalist as possible, so I've got money in the bank, so that when I have to pay more I have it.

"There is no entertainment," she continues. "I don't go anywhere. ... I can't remember the last time I bought clothes."

Right now, Winkler figures, she has enough saved to cover the expected shortfall for 22 months once David's assisted living bill eclipses their income and assistance.

And after that? She goes silent. She squares her jaw.

There is no answer.

Finding care, making it work

David lives in room 6 of an Ashley Manor Memory Care facility in Boise, a cozy clapboard and brick single family home on a quiet street of modest houses, recreational vehicles and American flags.

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The assisted living facility is home for up for 10 men and women with dementia. It has a bright kitchen where residents dine and a living room filled with overstuffed furniture. Outer doors are locked to prevent wandering. Staff members are on hand 24 hours a day.

On the plus side, it is not a nursing home. For now, David is well enough to live in his own space, to watch the squirrels romp outside his window. On the minus side, it is not a nursing home, so the embattled federal Medicaid program does not help pay for it.

“It is very difficult to find assisted living to provide care for dementia patients under Medicaid,” said Robert Vande Merwe, executive director of the Idaho Health Care Association, the trade group for the state’s nursing homes and assisted living facilities.

“It’s not even just the poor,” he said. “It’s the middle class that’s up the creek. Many will end up in nursing homes because there’s not enough beds in assisted living for Alzheimer’s patients in Idaho. The reason is that Medicaid doesn’t pay enough for assisted living.”

Although age and dementia do not discriminate by gender or income level, women are the ones most often left patching together long-term care for loved ones and living with the financial consequences.

“It’s primarily the daughters, the sisters, the wives, the mothers,” said Melissa Radloff, project manager of a nonprofit organization called Legacy Corps, whose volunteers provide respite for caregivers. “These are the people who step up. . . . They have to come up with some kind of resilience, some kind of strength day to day.”

So Winkler makes her regular rounds: Tuesdays and Thursdays to the grocery store for donations, the dumpster for produce, the food bank. Wednesday mornings to Ashley Manor, where she knocks and hopes the man she married 31 years ago greets her with a glimmer of recognition.

One recent Wednesday, David is waiting at the door. He is dapper in a light gray T-shirt, dark gray sweat pants and a red, white and blue beaded choker, a remnant of the July 4 holiday. Winkler hands a bag of donated pastries to the aide on duty.

The Winklers hold hands and walk to David’s room. She helps him fold the navy blue comforter and place it on the foot of his bed. They sit, hips and shoulders touching. He keeps his hand on her knee.

She tells him about the chickens and the neighbors who found a den of foxes on their property. He points out that the clock on the wall tells two different times. It doesn’t.

“I don’t know why,” he says.

“All that matters is that it’s Wednesday,” she tells him, “our day.”

When prompted, he reminisces about the young men he taught at the correctional facility, about his time in the Air Force, about their early courtship.

“I met Betsy through her brother. He lived on base. I lived on base. She told the fellows on the crew she was looking for a husband.” He smiles and blushes.

“A pen pal,” she corrects him, laughing.

“Why do I love her? I love her because she puts a lot of effort into loving me,” David says.

She brushes his cheek with her hand. “It’s not hard,” she says.

The visit is soon over. She heads to the minivan with the cracked windshield and bum door handle. Before she climbs in, she turns, and her eyes well up.

“I couldn’t ask for a better man. Too bad he’s not here anymore.” Then she stops. Smiles.

“He said my name again. The second time in two years.”

This has been a good day.

What is Medicaid? What is Medicare? And what do the programs cover?

What is Medicaid?

Medicaid is a joint federal and state program that is the single largest health insurer for children in the country, according to the American Academy of Pediatrics and the Children’s Hospital Association. The groups figure that 115,000 low-income children in Idaho are covered under the program, which also insures low-income parents, pregnant women, the elderly and disabled adults.

Who is not eligible for Medicaid in Idaho?

Under the Affordable Care Act, states were permitted to expand eligibility to low-income adults who were not previously covered. Idaho’s Legislature has not expanded Medicaid. Advocates for the working poor estimate that 78,000 Idahoans are in the so-called Medicaid gap.

How many people are covered in Idaho?

About 300,000 low-income children, pregnant women, adults, seniors and people with disabilities are covered by Medicaid in Idaho, according to the Henry J. Kaiser Family Foundation. That includes one in nine adults younger than 65, two in five low-income residents, two in five children, two in three people in nursing homes and two in five people with disabilities.

How is it different from Medicare?

Medicare is funded entirely through the federal government (and is financed with money from general government revenue, payroll taxes and beneficiary premiums). The standards for coverage for Medicare are set by the federal government. Medicare serves elderly and disabled people who receive Social Security. Because it was designed for adults, it does not include a benefit package for children. Income is not a consideration.

Who pays for long-term care?

Medicaid helps pay the costs of long-term care in nursing homes for those who are financially and medically eligible, but it does not cover assisted living facilities. “Some individuals may be required to help pay

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the monthly costs, which is called the participant contribution or share of cost amount,” said Chris Smith, a spokesman for the Idaho Department of Health and Welfare.

“Medicare covers short stays in a skilled nursing facility — up to 100 days per benefit period — after a three-day minimum, medically necessary, inpatient hospital stay for a related illness or injury,” Smith said. “Medicare does not cover long-term or custodial care.”

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