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U.S.

Family Caregivers Become More Crucial as Elderly Population Grows

Efforts are under way to ease strain of shrinking unpaid workforce key to care of seniors



To ease the strain of caring for his mother, Velma Jean DeFreese, who is 87 years old and has Alzheimer's disease, Stan DeFreese, left, enrolled her at a new adult day-care service in Biddeford, Maine. *PHOTO: YOON S. BYUN FOR THE WALL STREET JOURNAL*

By **JENNIFER LEVITZ**

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Velma Jean DeFreese, 87 years old, wrestles day and night with Alzheimer's disease.

So does her son, Stan, her full-time caregiver.

Formerly a busy nurse, Ms. DeFreese now can't be alone. She can't pick out her clothes, cook for herself, or recall that her husband died in 2012. The petite

widow relies on her son and daughter-in-law, with whom she lives, for everything.

“It’s hard, it’s hard,” said Mr. DeFreese, a 52-year-old engineer and jewelry-store owner who had just guided his mother into a new adult day-care center in Biddeford, Maine, near where they live, so he could grab a respite. “People don’t know what they’re getting themselves into.”

Strain on family caregivers is alarming many lawmakers and social-service providers, who are hearing more stories like Mr. DeFreese’s. They are pushing for new ways to assist the vast unpaid workforce of people who are crucial in part because they allow more seniors to age in place and reduce reliance on public subsidies such as Medicaid, a major funder of institutional health care for older Americans.

“Families have always been the backbone of our system for caring for people,” said Kathy Greenlee, the assistant secretary for aging at the U.S. Department of Health and Human Services. “Really, if we didn’t have them, we couldn’t afford as a country to monetize their care and we couldn’t replace, frankly, the love they provide to family members.”

About 40 million U.S. family caregivers provided unpaid care, valued at \$470 billion, to an adult with limitations in daily activities in 2013, according to AARP.

In Maine, the state with the oldest median age in the U.S.—44.2 years—the pressure on families is palpable. The percentage of the state’s population that is 65 and over is climbing and tops 18%, compared with 14.5% for the U.S. as a whole, according to the most recent census data.

That struggle isn’t new, but “demographics make it even a greater concern going into the future,” said Howard Degenholtz, a University of Pittsburgh associate professor of health policy and management who studies family caregivers.

The massive baby boom generation is barreling into old age with a smaller generation behind it, meaning a shrinking number of family caregivers will have to do more to help older people who require some support to remain at home.

“The math doesn’t add up,” said U.S. Rep. Michelle Lujan Grisham (D., N.M.), a member of a bipartisan congressional caucus, formed last year, focused on caregiving.

A caregiver to her own elderly mother, she recently introduced legislation for a national “Care Corps” program, modeled after the Peace Corps, to bolster the ranks of volunteer caregivers.

A bipartisan bill that passed the Senate would require the government to develop a “national family caregiving strategy.” Another bipartisan bill, introduced in Congress in March, calls for a tax credit of up to \$3,000 for eligible family caregivers.

Advocates are optimistic. “At least a couple pieces of legislation seem to have some legs,” said Gail Gibson Hunt, the president and chief executive officer of the National Alliance for Caregiving, a nonprofit coalition dedicated to the issue.

Democratic presidential contenders Hillary Clinton and Bernie Sanders have both said they support, among other ideas, giving unpaid caregivers credit in their Social Security benefits.



Maine has the oldest median age among U.S. states: 44.2 years. Above, a singalong at the Sam L. Cohen Center in Biddeford, Maine. *PHOTO: YOON S. BYUN FOR THE WALL STREET JOURNAL*

“Almost every family has this issue either themselves or they know someone close to them that has been touched with this,” said Victoria Walker, the national coordinator of the Family Caregiver Platform Project, a national coalition of organizations that is pressing state political parties to include caregiving in their platforms.

In Maine, the Southern Maine Agency on Aging, a nonprofit social-services organization, has opened two new adult day-care centers in the past year and a half. They now serve nearly 80 people and their caregivers.

“The baby boomers who are taking care of family have to work and it’s very difficult without any support,” said Polly Bradley, the agency’s director of adult day services. “Then we have spouses of the folks we serve—they are exhausted.”

At the Sam L. Cohen Center, the agency’s adult day service that opened in Biddeford in January, families pay \$18 an hour, or receive subsidies, to leave their loved ones. The clients, called “members,” have dementia or other cognitive disorders and typically live with family.

Many current members once helped this working-class area hum. Roger worked as a fire chief. Paul served in the Coast Guard. Ralph built roads and bridges.

Now, their families help them navigate the simplest of tasks.

Stan DeFreese left a network engineering job that required travel to tend to his mother, Velma Jean DeFreese. Mr. DeFreese now makes a living mostly at the jewelry store he and his wife own in Portland, Maine. He often squeezes in side engineering jobs late at night after he has gotten his mother to bed.

The relentless routine and stark role reversal triggered emotions as he recently spoke about it after delivering his mother to the Cohen Center.



Ralph Bouvier, a former bridge builder with dementia, and his wife, Maria, say goodbye to fellow members of the Sam L. Cohen Center. The Bouviers are moving to New Hampshire to live with a son. *PHOTO: YOON S. BYUN FOR THE WALL STREET JOURNAL*

“Wooh,” he said, exhaling loudly and wiping tears from his eyes. “You have to remember my mom, how she was when she was younger, how she took care of me. How she was there for me and everything else.”

For some family caregivers, the burden grows too heavy.

In the activity room of the Cohen Center recently, members enjoyed banana pudding and a singalong of “You are my Sunshine” and bid goodbye to 86-year-old Ralph Bouvier, a onetime bridge builder who has dementia.

His wife and caretaker, Maria Bouvier, who is 83, had hit her limit and the couple would be moving in with a son in Concord, N.H.

“He’s not the same person I married,” she said softly, standing to the side of the room. “Some days he’s good, and other days all hell breaks loose.”

Sometimes he thinks she is his mother. It hurts her to hear him rant or accuse her of stealing his watch or teeth. She reminds herself that it’s the disease talking, not her husband.

She lives for fleeting glimpses of the man she married. At every checkup, when the doctor asks Mr. Bouvier to write one sentence, he pens, “I love my wife.”

A ruggedly handsome guy with a tidy buzz cut, Mr. Bouvier donned pressed jeans and plaid shirt, and, as is his personal tradition, wore a pen and two cigars in his left shirt pocket.

“You’re looking good Ralph,” a staff member offered.

“I take good care of him,” Ms. Bouvier said.

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