PERSPECTIVE | MAGAZINE

Longterm caregiving for a family member is a labor of love — and a financial burden

My mom stepped up to care for my grandma. I know if I need to, I'll do the same.

By Lauren Booker Globe Staff, Updated July 13, 2026, 5:30 a.m.

ADOBE STOCK IMAGE; GLOBE STAFF ILLUSTRATION

When I was a kid, people called me my mother's shadow. We both had small glasses and rich brown skin, and wherever she went, I followed. My mother, Sylvia Wilson, shared a similar bond with her mother, Betty Hill, though forged through much harder circumstances. As a child, my mom had frequent seizures that required hospital visits. My grandmother was by her side.

So, when my grandmother fell ill in her late 50s, my mother had a choice: send her to a nursing home or take care of her herself. It's a decision many people face with aging parents, especially now, as baby boomers reach retirement age. Remembering how her mother was always there for her, my mother decided to become my grandmother's caregiver.

"She was happier being with her daughter," my mom says. "She wanted to be home."

That was in 2003. She took care of my grandmother for the next 20 years, as her health challenges worsened. My mother cherished the time she spent with my grandmother. But she made sacrifices no one should have to, including her physical health and her financial stability.

Last year, there were 63 million family caregivers in the United States, according to the "Caregiving in the U.S." report by AARP and the National Alliance for Caregiving. Most were unpaid. My mother credits her caregiving for being the reason my grandmother lived as long as she did: She'd seen my grandmother neglected during short nursing home stays for rehabilitation. To put a price on caregivers' collective labor, their 49.5 billion hours exceeded $1 trillion in economic value for the US economy in 2024, another AARP report found.

"Caregiving is real work," Kathleen Romig, senior fellow at the Center on Budget and Policy Priorities, says. "What would our economy look like if we didn't have people raising kids or taking care of elders or taking care of family members with disabilities?"

I used to ask myself if I'd follow in my mother's footsteps if she needed care. *Could our bond be stronger than the things I'd have to sacrifice, the rising cost of living, and the lack of support for caregivers?*

It's a tough question, and I can't help but think of the concessions my mother has already made.

I saw my mother, a member of the sandwich generation, juggle mothering me, working as a school bus driver, and taking care of her mother. My grandmother battled diabetes, high blood pressure, congestive heart failure, and a few mini strokes. Those ailments kept her from driving a car and required her to use a walker. My mother drove her, cooked her food, and administered her insulin shots.

In 2019, my grandmother was diagnosed with kidney failure and lost the ability to walk. Nursing home staff told my mother she'd have to quit her job to bring my

grandmother home. So she did. For five years, my mother performed even more intensive care: administering bed baths, providing wound care, turning my grandmother in bed.

“I had to learn how to do total care,” my mom says.

Fifty-five percent of Black family caregivers provide high-intensity care, like my mother did, according to a 2025 AARP Caregiving in the US African American/Black Family Caregivers profile. That’s about 10 percentage points higher than the AARP’s estimate of high-intensity caregivers among all adults.

In 2024, my mother was so worn down by the physical labor, emotional stress, and administrative work of caregiving. During a routine check up, her doctor observed signs of an impending heart attack or stroke. She was rushed to a hospital, where she was diagnosed with atrial fibrillation, a heart rhythm disorder.

Sustained stress can wear down caregivers’ immune and cardiovascular systems, says Paula Sherwood, a nurse scientist and professor at the University of Virginia. “It’s like walking down the street and meeting a bear. You have this fight or flight response,” she says. “And normally once the situation resolves, then the bear goes away. Then everything goes back down to normal. But for a caregiver, the bear never goes away.”

My mother’s AFib weakened her body and prevents her from walking unassisted. However, when she applied for Social Security Disability Insurance, she was denied — she hadn’t worked enough over the previous 10 years because she had a work gap from taking care of my grandmother. Her Social Security retirement projections have also taken a hit, because the calculation is based on a person’s 35 highest-earning years.

“It hurts, but there’s nothing you can do about it,” she says. “I can’t find a job because of my health problems… I can’t go back to driving a school bus.”

Legislation could help. The Social Security Caregiver Credit Act would help boost Social Security retirement credits by up to five years for caregivers who left the workforce but provided care for at least 80 hours per month. There's also the Credit for Caring Act that would give eligible caregivers a tax credit of up to $5,000 a year. US Senator Ed Markey's "Caring for Caregivers" agenda is crafted to address the needs of family caregivers, including increasing access to respite care.

Markey says he was inspired by watching his father care for his mother after she was diagnosed with Alzheimer's, with limited assistance. "These caregivers are heroes, but heroes need help," he told me. "My father deserved more help, more support. Your mother deserved more help, more support. Millions of families have a story that mirrors my family's story and your family's story."

Bills in the Caring for Caregivers agenda are currently in the Senate, along with the Social Security Caregiver Credit Act. The Credit for Caring Act was referred to the House Committee on Ways and Means. With President Trump preoccupied with a long-shot election overhaul bill, I don't have hope that any of these bills will become law anytime soon.

After my mother's AFib diagnosis, I confronted the question I had asked myself years earlier.

I chose to be there for her as much as I could, flying to care for her during extended stays. I drove her to doctors' appointments, managed her medicine, and cooked her meals. I provided emotional support through her new reality — and through my grandmother's death months later.

Right now, she doesn't need my full-time care. But if that changes, I'll be there.

Lauren Booker can be reached at lauren.booker@globe.com.

Show comments