

Helping the Helpers

New state laws support the millions of Americans who minister to aging relatives and form the backbone of the nation's long-term care system.

BY JULIA C. MARTINEZ

When Kristen Mitchem's father was diagnosed with a malignant brain tumor in 2013, the North Carolina pastry chef quit her dream job at a five-star restaurant to help care for him in Oklahoma.

After several surgeries, Alphus Mitchem needed round-the-clock attention to recuperate at home, where patients report a higher quality of life.

Overnight, Kristen, her mother and sister joined the ranks of the 42.1 million family caregivers who form the backbone of the nation's long-term care system. Their work entails much more than cooking, cleaning and doctors' trips.

Today, nearly half of them also manage medication, monitor feeding tubes, dress wounds and perform other tasks normally done by health care professionals. Valued at \$450 billion a year, family caregiving is a critical component of the U.S. economy, outstripping public spending for Medicaid in 2012.

"I didn't consider it a sacrifice to leave my job," Kristen Mitchem says. "When you spend your whole life with your parents taking care of you, it's something I didn't think twice about."

Still, because she's not trained as a caregiver, Kristen says the job has been

frustrating at times and has caused setbacks for her father.

With the nationwide shift to home-based care from institutional care, family caregivers like the Mitchems lack supports, including flexibility, training and respite care, which could lead to caregiver burnout.

Numerous studies show demand for long-term services and supports will soon outpace the availability of potential family caregivers, according to data from AARP's Public Policy Institute, the National Alliance for Caregiving and other organizations.

The looming shortage of caregivers reflects a rapidly aging population, longer lifespans, a preference for home-based care, the need for more chronic disease care and changes in family demographics. Adding to this are the leading edge of baby boomers, who will turn 69 this year. Many never married or have fewer children to care for them than did their parents.

"If you look at the ratio of people who need care and people available to care for them, we're looking at a sleigh ride going downhill," says Susan Reinhard, director of AARP's Public Policy Institute. "It's a steep decline over the next 20 to 30 years. We have fewer people available to care for people who need it."

Without unpaid family caregivers, the economic cost of long-term care to state and federal governments would be a larger burden on Medicaid budgets.

To head off a potential crisis—and in the absence of a substantial federal long-term care strategy—state legislatures are finding ways to help fill the gap.



Representative
Brian Crain
Oklahoma

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CARE Acts in New Jersey, Oklahoma

Lawmakers in New Jersey and Oklahoma enacted versions of the Caregiver Advise, Record and Enable, or CARE Act, effective in 2014. The law requires hospitals, when a patient is admitted and with his or her consent, to record the caregiver's name; to notify that caregiver before the patient is discharged; and to help prepare the caregiver for the medical or nursing tasks he or she is being asked to perform for the patient at home.

The ultimate aim is to keep patients healthy

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Representative
Harold Wright
Oklahoma

after discharge and to avoid costly readmissions. Nationally, one in five Medicare recipients who leaves a hospital is readmitted within the first 30 days, costing Medicare \$17.5 billion a year in additional hospital bills.

The Centers for Medicare and Medicaid Services started penalizing hospitals in 2012 with lower reimbursements for readmissions within a month of discharge as part of the federal government's effort to pay health care providers based on the quality of care they perform.

Oklahoma Senator Brian Crain (R), sponsor of the CARE Act, along with Representative Harold Wright (R), says the law was personal. Both his parents died of Alzheimer's disease within a decade of one another. His father cared for Crain's mother during her illness.



Speaker
Vincent Prieto
New Jersey

"I see how difficult it is for caregivers. It is a learning process, and there are a lot of things they don't have at their disposal."

"Caregiving was hard on dad," Crain says. "From that standpoint, I have a lot of sympathy for the plight of caregivers who care for loved ones being released from a hospital."

Assembly Speaker Vincent Prieto (D), who sponsored New Jersey's more detailed CARE Act along with Senator Joseph Vitale (D), says he, too, understands the toll caregiving can take. His elderly mother-in-law lives in her own home and is being cared for by his wife.

"I see how difficult it is for caregivers," Prieto says. "It is a learning process, and there are a lot of things they don't have at their

disposal. Somebody needs to help them out ... so they can help our elderly be healthy and live to their full potential."

Both lawmakers say their states will benefit from fewer hospital readmissions.

Hospitals' Response

Initially, hospitals in both states had concerns they would be held legally liable if caregivers did not provide proper care and believed the legislation was an unnecessary mandate. New Jersey's association also had concerns that the bill's original provisions



Senator
Joseph Vitale
New Jersey

could delay a patient's discharge.

"We didn't support it because we felt we were doing this already," says Lynne White, spokeswoman for the Oklahoma Hospital Association. But "at the end of the day, we withdrew our opposition," she says. "If we can go the extra step to make our services more patient friendly, that's what we want to do."

New Jersey's hospital association said it took a neutral position after working closely with AARP and the bill sponsors. "It was a very collaborative and productive discussion and we ultimately came up with final language that was beneficial to the patient and that all sides were happy with," says Kerry McKean Kelly, spokeswoman for the association.

Crain and Prieto indicated that hospitals in their states took a softer tone after realizing that the legislation could reduce readmissions and associated penalties. "That was certainly a conversation and selling point we had with the hospital association," Crain says.

In Hawaii, however, lawmakers sponsoring a CARE Act bill were blocked by the Healthcare Association of Hawaii, which took issue with the bill's basic premise. "AARP wants hospitals to train unqualified people to perform complex clinical, medical and nursing tasks," says George Greene, president and CEO of the association. "It makes no sense to force hospitals to do this, and it is not safe for patients."

AARP disagrees. "We can't ignore the fact that right now, family caregivers are cleaning wounds, giving injections, managing complex

FAMILY CAREGIVER AWARDS

To recognize the state elected officials who were integral in creating legislation in 2014 to support family caregivers, AARP honored the following legislators and governors with "2014 Capitol Caregiver" awards.

Senator Hannah-Beth Jackson, California
 Assembly Speaker Toni Atkins, California
 Assemblywoman Cheryl Brown, California
 Governor Dannel Malloy, Connecticut
 Senator Terry B. Gerratana, Connecticut
 Representative Theresa W. Conroy, Connecticut
 Representative Jason Perillo, Connecticut
 Representative Valerie J. Longhurst, Delaware
 Senator Suzanne Chun Oakland, Hawaii
 Senator Rosalyn Baker, Hawaii
 Senator Vaneta Becker, Indiana
 Senator Ed Charbonneau, Indiana
 Representative Edward Clere, Indiana
 Senator Patricia Miller, Indiana
 Senator Robert Hogg, Iowa
 Representative Chip Baltimore, Iowa
 Senator Morgan McGarvey, Kentucky
 Senator Reginald Thomas, Kentucky
 Representative Joni L. Jenkins, Kentucky
 Representative Tommy Thompson, Kentucky
 Representative Robert A. Johnson, Louisiana
 Senator Gale D. Candaras, Massachusetts
 Representative Anne M. Gobi, Massachusetts
 Representative Christopher M. Markey, Massachusetts

Representative James O'Day, Massachusetts
 Senator Sandra L. Pappas, Minnesota
 Senator Kathy Sheran, Minnesota
 Representative Carly Melin, Minnesota
 Representative Dan Schoen, Minnesota
 Senator Terry C. Burton, Mississippi
 Senator Briggs Hopson, Mississippi
 Representative Mark Baker, Mississippi
 Representative Bobby Moak, Mississippi
 Senator Kate Bolz, Nebraska
 Senator Sue Crawford, Nebraska
 Senator Robert W. Singer, New Jersey
 Senator Joseph F. Vitale, New Jersey
 Assembly Speaker Vincent Prieto, New Jersey
 Assemblywoman Nancy F. Munoz, New Jersey
 Senator Michael Padilla, New Mexico
 Representative Tomás Salazar, New Mexico
 Governor John Kasich, Ohio
 Governor Mary Fallin, Oklahoma
 Senator Brian A. Crain, Oklahoma
 Representative Harold Wright, Oklahoma
 Senator Thomas Alexander, South Carolina
 Representative Rebecca Chavez-Houck, Utah
 Senator Brian Shiozawa, Utah
 Delegate Barbara Evans Fleischauer, West Virginia

medications and much more," says Elaine Ryan, vice president for state advocacy and strategy at AARP.

The hospital group was also concerned that a CARE Act could cost Hawaii's public hospitals millions of dollars in additional staff and liability protection.

Nonetheless, Hawaii Senator Suzanne Chun Oakland (D), the Senate sponsor, says she is not giving up on the bill, particularly since the average Hawaii resident lives so long—the average lifespan is 81 years on the islands, compared to the U.S. average of 78 years.

Caregivers Unprepared

Oklahoma's CARE Act came too late for Kristen, her mother Cheryl and her sister Deidra, who learned through trial and error the complex tasks involving medication management, feeding tubes, wound care and other tasks normally performed by trained health care professionals. "They never showed

me anything. We have learned to care for my husband by watching the health providers," Cheryl Mitchem says.

Weeks after 72-year-old Alphas Mitchem was discharged from the hospital the first time, Cheryl says her husband was rushed back with seizures because she and her daughters weren't aware of certain medicines he should have been taking. Since then, she says, at least one other return trip also was triggered by a lack of instruction.

The Mitchems' story illustrates the plight of millions of family caregivers nationwide: Some 46 percent face difficult medical and nursing tasks for which they are unprepared, says Kathy Kelly, CEO of the Family Caregiver Alliance, a national research and advocacy organization.

Family caregiving can also take a personal and financial toll. Many caregivers lose earnings, pensions and Social Security benefits and spend down their savings.

"There are many people who put their



Senator
Suzanne Chun Oakland
Hawaii

"If we do not make this a top priority, there will be a crisis."

personal and financial lives on hold to care for a loved one," Kelly says. "You're providing care for a person who needs it but impoverishing someone else in the process." Those who earn less than \$40,000 are at greatest financial risk, she says.

Family caregivers learn quickly that most employer-provided health insurance does not cover long-term care. Neither does Medicare, which helps pay up to 100 days in a skilled nursing facility under certain conditions or part-time home health care. To get Medicaid long-term care coverage, a person must meet specific income and asset criteria that vary from state to state.

Other States Consider CARE Act

Illinois and Kansas are among about a dozen states considering CARE Act legislation.

Elsewhere, legislatures in Delaware, Hawaii, Mississippi and New Mexico formed committees last year to study how their states support family caregivers and how they can help more, while a dozen state legislatures passed a variety of related initiatives. Among them was Rhode Island, which expanded the state's disability insurance program to cover family leave, similar to laws that have been adopted in California, Minnesota and New Jersey in previous years.

In rural and underserved areas, where doctors are often scarce, lawmakers have supported family caregivers by passing legislation that expands nurses' roles. In some of the states, including Kentucky, the laws expand nurse practitioners' scope of practice, enabling them to prescribe certain medications without a collaborative agreement with a doctor. Other states, like West Virginia, now allow nurses to delegate tasks to caregivers.

In Alabama, a state coalition worked to expand its respite care for family caregivers. California, Massachusetts, Mississippi and Wyoming passed laws to protect the interests of vulnerable, incapacitated adults who need guardians.



Increasing Demand

Research leaves no doubt that an aging population will require more care.

A U.S. Department of Health and Human Services study concluded that more than 70 percent of people age 65 and older will need long-term care services for an average of three years. Some 40 percent have a chance of entering a nursing home. Another study in 2010 by AARP found there were seven potential caregivers for each adult over age 80. By 2050, that ratio could drop to three to one.

There has been little action at the federal level. The 2000 National Family Caregiver Support Program provides annual grants to states to support some family caregivers, but funding has stayed at roughly \$155 million or less, despite the increasing demand.

In 2010, Congress passed a law to provide training and support for family members who care for post-9/11 military veterans. This pool of family caregivers comprises about 2.6 percent of the whole. Other comprehensive bills are pending but face uncertain odds.

AARP's Reinhard argues that state initiatives "are

the first line of defense against institutionalization." They will help family caregivers avoid burnout and care for their loved ones at home and in the community more efficiently and effectively, she says.

However, "substantive action varies tremendously from state to state," says John Schall, CEO of the Caregiver Action Network in Washington, D.C. "Some states have figured out the importance of supporting family caregivers," while others have not.

Hawaii's Senator Chun Oakland wants her state to be in the former category.

"If we do not make this a top priority, there will be a crisis," says Chun Oakland, who proposes that caregiving be taught in schools. "We need to build our capacity, so we do not have our kupuna [elders] and other vulnerable people left with no support."

As state legislatures reset their agendas for the coming year, Reinhard offers this thought for state lawmakers: "You're either a caregiver now or will need one in the future. Caregiving will affect you personally and directly. States need to prepare for the future and at a faster pace than we're doing it now."



FAMILY CAREGIVERS By the Numbers

66%

Portion of family caregivers who are female, 34 percent of whom care for two or more people

19%

Portion who report receiving some training but want more

78%

Portion who report needing more help with at least 14 different caregiving topics

20.4 hours

Average time caregivers spend each week providing care

72%

Portion who live within 20 minutes of their care recipient

\$4,570

Annual related expenses for caregivers who live near their loved one

\$8,728

Long-distance caregivers' annual related expenses

11%

Those who report that providing care has harmed their own physical health

24 %

Portion who report caregiving has harmed their work performance and shortened their time spent at work

70%

Portion of working caregivers who have made some job change due to caregiving

Sources: AARP, The National Alliance for Caregiving, Gallup Surveys, 2012-2014.