Caregivers Fill Crucial Role But Don’t Get Much Help

Their care of loved ones defrays costs that would otherwise have to be borne by the health care system, but they too often go it alone.

By Susan Ladika

Anna Boyle is struggling to figure out how to care for her mother. After a string of health issues put Doris Boyle in and out of Boyle’s care for the past three years, the 88-year-old was diagnosed with Alzheimer’s disease. (Names have been changed at the request of the family.) She has been living with Boyle’s family full time since Thanksgiving.

“This year, her decline has just been unbelievable. Today she failed to recognize my daughter for the first time and she’s very confused,” the 53-year-old legal assistant from Tampa, Fla., said shortly before Christmas.

“She’s been a strong woman all her life,” Boyle says. “Now it’s almost like she’s a baby again at times.”

Soldiering on

Boyle is facing what millions of Americans must cope with each day—taking care of loved ones who cannot properly care for themselves. And often these families soldier on, with no or limited outside support. The numbers are staggering, with 43.5 million Americans—or nearly 15% of the population—providing care to a loved one, a 2015 study by AARP and the National Alliance for Caregiving found.

As the population ages, the caregiving situation is expected to become more acute. The prime age for caregivers is 45 to 64, according to AARP. Right now, there are seven people in that age group for every person age 80 or older. By 2030, there are projected to be only four potential caregivers for every person age 80 or older.

Caregivers spend an average of 24 hours a week on caregiving, and nearly 60% have to tackle complex medical tasks, such as giving injections or dealing with catheters. Most have received no training.

“You cannot ignore these people,” Susan C. Reinhard, AARP’s senior vice president, says of caregivers. The unpaid care they provide came to $470 billion in 2013.

And a third of caregivers do it all on their own, without any paid or unpaid assistance. In fact, many have to pay out of pocket to provide financial assistance for their loved ones. A report by the insurer Genworth found they pay an average of $10,000 out of pocket a year.

All that unpaid care had an economic value of $470 billion in 2013, according to an AARP report. “The problem is that family caregivers are invisible, but you cannot ignore these people,” says Susan C. Reinhard, senior vice president at AARP. If the caregiver gets

### Physical, emotional, and financial stresses from caregiving

<table>
<thead>
<tr>
<th>Physical strain</th>
<th>Not at all</th>
<th>Very much a strain</th>
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<td>28%</td>
<td>7%</td>
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<th>Emotional stress</th>
<th>Not at all stressful</th>
<th>Very stressful</th>
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<td>16%</td>
<td>20%</td>
<td>22%</td>
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<th>Financial strain</th>
<th>Not at all</th>
<th>Very much a strain</th>
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<td>39%</td>
<td>10%</td>
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Source: AARP, “Caregiving in the U.S.,” June 2015
sick or is hospitalized, “things can fall apart quickly,” acknowledges Philip Painter, chief medical officer at Humana.

Yet they often are ignored. That can be to the peril of the patient and the caregiver alike.

Takes a toll
Caregiving may take a toll on the health of caregivers. Research has shown that the health of family caregivers can be adversely affected by the burden, notes Painter, and the risk increases with time and as the condition of the person being cared for worsens. A Genworth study found that caregiving negatively affected the health of more than 40% of caregivers, and a third reported extremely high levels of stress. AARP found 17% of respondents were in fair or poor health.

Tennessee’s CHOICES program makes health plans take into account the needs of caregivers, says Patti Killingsworth, chief of long-term services at TennCare, the state’s Medicaid program.

It would seem to be in the interest of payers to support caregivers and keep them healthy. An overburdened, stressed-out caregiver might end up needing medical care for any number of conditions. The payers, covering the bills of those being cared for may also be affected. If a caregiver can’t keep up with her caregiving responsibilities because she is sick, the person being cared for may be at risk for hospitalization or admission to a skilled nursing facility.

Sandy Wollenhaupt, of Russell, Ky., was fortunate in many ways when she was caring for her mother, Imogene Vallance, who died in 2013 at age 80. Wollenhaupt is a nurse, and thanks to an understanding employer, she was able to come home during the workday to help care for her mother. Her husband, kids, and sister-in-law—also a nurse—pitched in. Still, it was difficult to do all that needed to be done, particularly as her mother lost mobility. Wollenhaupt’s blood pressure shot up, and she had to start taking medication to control it.

“It was frustrating and hard to try to balance being a mom and a daughter and full-time employment. A family is asked to do a lot if they want to keep family members at home,” she says.

Caregiving can also undermine people’s financial well being. Caregivers often must dip into savings to cover the out-of-pocket expenses of their loved ones, cut back on their work hours to provide care—or drop out of the workforce altogether. Boyle, the Tampa legal assistant, faces a common dilemma. She is worried about her mother having the care she needs when she and her supportive family are either at work or at school. “If I have to drop out of work, it would bankrupt us,” she says. She has lined up a spot at a nearby adult daycare center to provide care as needed.

More than half of caregivers said they had to work fewer hours, and one quarter said they missed out on career opportunities because of their caregiving responsibilities, Genworth found.

An AARP survey found that 10% of caregivers aged 50 and older quit their jobs or took early retirement to provide care, while 17% took a leave of absence. Those who left the workforce lost about $300,000 in wages and benefits. “We need to help them stay on the job,” says AARP’s Reinhard.

12 weeks of paid leave
The Family and Medical Insurance Leave (FAMILY) Act, which has been introduced in Congress, would provide workers at all companies with up to 12 weeks of paid leave if they are dealing with their own serious health condition or that of a family member. Workers would be able to earn up to two thirds of their monthly wages. California, New Jersey, and Rhode Island are the only states that offer paid family medical leave.

Almost half of states have unemployment insurance available for workers who voluntarily leave their jobs to serve as caregivers, but it’s seldom publicized and can be hard to collect, a study by AARP, the Commonwealth Fund and the SCAN Foundation found. Kathleen Kelly, executive director of the Family Caregiver Alliance, a national not-for-profit group based in California, had no idea before the study was conducted that California had unemployment insurance for caregivers. “We were as sur-

Most preferred financial support policy
Show caregivers the money!

| Program where caregivers are paid for some hours of care | 26% |
| Income tax credit | 32% |
| Partially paid leave from work | 13% |
| Not sure | 25% |

Source: AARP, “Caregiving in the U.S.,” June 2015
prised as anybody else. It’s there in theory. In practice, I’m not sure how much it’s utilized.” One possible
source of financial assistance for caregivers comes from Medicaid. Most states have programs that use a
waiver to allow someone who is on Medicaid to select a personal care attendant, such as a family member.

The caregiver is then paid by Medicaid, Reinhard
says. Program specifics can vary from state to state.
However, “for the vast majority of middle-income
Americans, there’s not much financial assistance,”
Kelly says.

**Insurers take steps**
A few health plans have started to take some steps to
recognize and support caregivers. Tennessee is at the
forefront of caring for the patient and the caregiver
through CHOICES, which provides long-term care
through TennCare, the state’s Medicaid program.

The program is available for adults aged 65 and
older, and for younger adults who have a physical
disability. They must qualify for Medicaid long-term
services and supports, and be unable to do everyday
activities, such as taking medications and toileting.

Participants must either need the level of care pro-
vided in a nursing home or be at risk of having to move
to a nursing home if they don’t receive the extra care.
CHOICES can provide in-home care and help people
stay in their homes longer. Payers should appreciate
that remaining at home is far less costly than nursing
home care. According to Genworth’s 2015 Cost of
Care Survey, the cost of hiring a home health aide or
homemaker services worker averages $20 an hour
nationally. In comparison, living in an assisted-living
facility averages $43,200 per year, while a semiprivate
room nursing home costs an average of $80,300 per
year, and a private room costs $91,200.

As part of CHOICES, health plans now must take
the needs of the caregivers into account, not just those
of the patients. “It recognizes the very important role
that caregivers play,” says Patti Killingsworth, chief of
long-term services with TennCare.

**In-home assessment**
Within 10 business days, the state’s three Medicaid
managed care organizations—Amerigroup, BlueCare
Tennessee, and UnitedHealthcare Community Plan—
are required to do an in-home assessment of both the

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**Projected long-term care expenditures, 2015–2050**

![Graph showing projected long-term care expenditures from 2015 to 2050 with breakdowns for Total, Medicaid, and Out-of-pocket expenditures.](source)

**Source:** American Council of Life Insurers, “Who Will Pay for Our Long-term Care?,” October 2014

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**Long-term care expenditures for the elderly**

<table>
<thead>
<tr>
<th>Current distribution</th>
<th>Medicaid 32.9%</th>
<th>Medicare 33.7%</th>
<th>Private ins. 6.5%</th>
<th>Other 7.2%</th>
<th>Out-of-pocket 19.8%</th>
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<tbody>
<tr>
<td>With an expansion of LTC insurance coverage</td>
<td>Medicaid 24.9%</td>
<td>Medicare 24.7%</td>
<td>Private insurance 26.0%</td>
<td>Other 7.8%</td>
<td>Out-of-pocket 10.9%</td>
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**Source:** American Council of Life Insurers, “Who Will Pay for Our Long-term Care?,” October 2014
Long-term care insurance could help defuse the looming baby boom retirement ‘disaster’

Long-term care is expensive for all concerned—those getting it, their family, caregivers, and taxpayers. And the situation is only expected to get worse as the American population ages.

“Everybody is acutely aware that as 10,000 baby boomers hit the senior citizens ranks every day, it’s a potential disaster,” says Marjorie Keymer, vice president and medical director of claims for the insurer Genworth.

Already, long-term care for seniors costs an estimated $231 billion each year, according to the American Council of Life Insurers (ACLI). That equals 7.5% of all money spent on health care in a given year. Medicaid and Medicare each cover about a third of those costs, while patients and their family members shoulder 20% of the burden, or $46 billion in out-of-pocket expenditures.

Spending on long-term care is expected to soar to almost $400 billion by 2030, while the number of employees paying taxes will shrink. In 2010, there were nearly three workers paying taxes for every retiree; by 2030, there will be just two per retiree.

One possible way to spread the financial burden is through private long-term care insurance. The ACLI calculates that if one quarter of consumers purchased long-term care insurance, Medicaid would wind up shouldering 25% of the country’s long-term care costs and individuals about 11%, while private insurance coverage would jump from less than 7% today to 26% in 2050.

But for consumers, this may not look like such a good deal. Premiums for long-term care insurance have gone up while the benefits have become less generous. Actuarially, it’s a difficult business to be in. “The reality is very few companies are left,” says Chris Conklin, senior vice president of product design for Genworth.

Several big players, such as Prudential and MetLife, no longer sell individual long-term care policies. Genworth, Mutual of Omaha, and John Hancock have stayed in the market.

The prices for long-term care policies rose an average of 8.6% from 2013 to 2014. An unmarried 55-year-old man paid an average of $1,060 for $164,000 in coverage in 2014, while an unmarried 55-year-old woman paid $1,390, according to the American Association for Long-Term Care Insurance. A married 60-year-old couple paid, on average, $2,170 for $328,000 in coverage.

Premiums vary with an individual’s age when purchasing the policy, the maximum daily or monthly amount the policy covers, and how long the policyholder will wait until the policy kicks in. Often, people choose a 90-day wait. Typically, policies today provide coverage for three or four years, and criteria are often an inability to do the “activities of daily living,” such as bathing, dressing, going to the bathroom, and feeding oneself.

If someone wants to file a claim with Genworth, a registered nurse will visit the individual and his family caregiver to assess his physical and cognitive functions, says Keymer. The nurse then will draw up a plan of care, outlining the type of assistance needed. Needs are reassessed over time.

Currently, nearly 7 million Americans have long-term care insurance, according to ACLI. The number of people covered by the insurance climbed 17% between 2007 and 2013. Much of that growth is in hybrid policies, such as ones that combine life insurance and long-term care insurance. A consumer would typically purchase a whole life policy, with long-term care coverage as a secondary benefit. The hybrid policies were introduced about 10 years ago.

Genworth, Guardian, and Nationwide are among the companies that sell hybrid policies. Consumers are advised to be a little wary because some hybrid policies offer very skimpy long-term care coverage. A hybrid policy generally costs about 5% to 15% more than a standalone life insurance policy. If the hybrid policyholder becomes ill or injured, the death benefit can be accelerated and used to pay for long-term care. However, that will reduce the life insurance payout to heirs when the person dies.

“It ends up being a living benefit of a life insurance policy,” says Frank Chechel, second vice president of life product management at the Guardian Life Insurance Co. of America.

State Partnership Programs, which link certain long-term care policies offered by private insurers with Medicaid, are another choice for people entering their care-need years. With these policies, if you have, say, $100,000 worth of coverage you can apply for Medicaid and still retain $100,000 worth of assets. Those are above a state’s Medicaid asset limit.

In most states, the limit is $2,000 for a single person.

So, you could retain $102,000 worth of assets. The ACLI says partnership policies are available or pending in 42 states.

new member and his or her caregiver and develop an initial care plan, she says. That plan includes actions that are necessary to support the member and to help maintain the health and well being of caregivers to help ensure their ability to provide care to the member. For example, caregivers might receive some training that would help them in their caregiving duties or other types of support, such as respite care or referrals to support groups.

The goal of the program is to help allow people...
who need long-term care services and supports to receive that care in their homes and other community based settings.

“At the same time, we do want to support caregivers, and absolutely recognize that supporting caregivers is an essential aspect of helping older adults and people with disabilities live in their own homes,” Killingsworth says.

**Humana at Home program**
The challenges and burdens also are recognized by Humana, which has a strong presence in the Medicare Advantage market. The insurer has extensive resources for caregivers through its plans and on its website. As part of its Humana at Home program, for example, the insurer helps older adults to remain in their homes through services such as a personal care manager who is a nurse or licensed clinical social worker. The care managers talk with both the Humana members and their caregivers regularly, and they provide telephone or in-home services for about 1 million Humana members, says Painter, the chief medical officer.

“They can fall apart quickly” if the caregiver gets sick, says Philip Painter, Humana’s CMO.

Yet caregivers are often ignored, and that can be perilous for caregiver and patient alike.

They also have access to local resources for members and caregivers, such as information on adult daycare facilities or transportation options. “Over time, we’ve built up this very robust community resources directory,” notes Painter.

All caregivers can access Humana’s Caregiver’s Toolkit (even if you are not a Human customer). The booklet has pages for recording medications and medical conditions and some basic tips for how caregivers can take care of themselves, including the useful admonition to set some time aside for yourself.

Meanwhile, state and federal lawmakers are pushing ahead with legislation designed to help caregivers. The CARE (Caregiver Advise, Record, Enable) Act is designed to help caregivers stay informed when a loved one is in the hospital and to prepare them to care for that person once discharged. AARP is championing the legislation, which has been enacted by 18 state legislatures and is under consideration in 22 others. Here are the three main provisions of the law:

- Hospitals or rehabilitation facilities are required to record the name of the family caregiver when a loved one is admitted for treatment.
- The family caregiver must be notified if a loved one is going to be discharged to another facility or released to the home.
- Hospitals and rehabilitation facilities are required to provide explanations and in-person instruction about medical tasks that a family caregiver will need to provide at home, such as transferring a person out of a wheelchair, giving medications, or caring for wounds.

This may all seem like common sense—and none of it costs very much. Yet, says Kelly, these simple efforts often aren’t made.

One goal of the CARE Act is to reduce hospital readmissions, and offering instruction to caregivers may help in that regard, Reinhard says. Oklahoma became the first state to enact the CARE Act in 2014. It was supported by Republican Gov. Mary Fallin, who had personal experience caring for her bedridden mother while raising a family of her own.

There are several efforts at the federal level that would ease the caregiver’s burden. At the end of 2015, the Senate approved the RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act, which would set in motion a national strategy for supporting caregivers. The bill is pending in the House.

Earlier in 2015, members of Congress formed the Assisting Caregivers Today caucus, designed to bring more attention to the challenges facing caregivers. Rep. Lujan Grisham, a New Mexico Democrat, introduced a bill to create a national Care Corps, modeled after the Peace Corps, in which volunteers would provide services designed to help older adults and those with disabilities continue to live independently. Meanwhile, Rep. Nita Lowey, a New York Democrat, introduced the Social Security Caregiver Credit Act.

The plan would provide Social Security earnings credit for caregivers who leave their jobs or cut back their work hours to care for a loved one. Hillary Clinton has come out in support of Social Security credits for caregivers and has proposed a $6,000 tax credit to cover expenses of those who serve as caregivers.

“**For the vast majority of middle-income Americans, there is not much financial assistance**” for caregivers, says Kathleen Kelly, executive director of the Family Caregiver Alliance.

Susan Ladika is based in Tampa, Fla., and has been a freelance writer for almost 20 years.