

Who will care for the care-Givers?

Some 40 million Americans give daily help to a parent, grandparent, relative or neighbor, assisting with basic things like dressing, bathing, cooking, medications or transportation

“I should have put his socks back on.”

The thought kept nagging me as I finished my clinic notes, replaying the afternoon in my head. My final patient of the day — a man with dementia — was a late addition to the schedule, after his daughter, herself a patient of mine, called to report he hadn’t been himself lately. We scheduled him for the last appointment, so she could join after finishing work across town.

She recounted the subtle changes she’d noticed in her father. He’d been eating less, sleeping more. He was less steady on his feet and seemed uninterested in playing with his grandchildren — an activity that normally filled him with irrepressible joy.

From her purse, she pulled out no fewer than eight pill bottles — each with a dose, time and frequency meticulously labeled. She handed me a handwritten transcript of his other recent appointments: an ophthalmologist, a neurologist, a cardiologist. As I examined him, her phone rang.

“Grandpa isn’t feeling well, sweetie,” she said. “There’s macaroni in the fridge. We’ll be home soon.”

She hung up and apologized for the interruption. Then she leaned over to pull his socks over his bare feet — socks I’d removed moments before and left on the exam table.

“I should have put his socks back on.”

There are some 40 million Americans like my patient’s daughter. Every day, they help a parent, grandparent, relative or neighbor with basic needs: dressing, bathing, cooking, medications or transportation. Often, they do some or all of this while working, parenting, or both. And we — as doctors, employers, friends and extended family — aren’t doing enough to help them.

According to AARP and the National Alliance for Caregiving, the [typical family caregiver](#) is a 49-year-old woman caring for an older relative — but nearly a quarter of caregivers are now millennials and are equally likely to be male or female. About one-third of caregivers have a full-time job, and 25 percent work part time. A third provide more than 21 hours of care per week. Family caregivers are, of course, generally unpaid, but the economic value of their care is estimated at [\\$470 billion](#) a year — roughly the annual American spending on Medicaid.

A recent [report](#) from the National Academies of Sciences, Engineering and Medicine suggests that society’s reliance on this “work force” — largely taken for granted — is unsustainable. While the demand for caregivers is growing because of longer life expectancies and more complex medical care, the supply is shrinking, a result of declining marriage rates, smaller family sizes and greater geographic separation. In 2015, there were seven [potential family caregivers](#) for every person over 80. By 2030, this ratio is expected to be four-to-one, and by 2050, there will be fewer than three potential caregivers for every older American.

This volunteer army is put at great financial risk. Sixty percent of those caring for older family members report having to reduce the number of hours they work, take a leave of absence or make other career changes. Half say they’ve gotten into work late, or had to leave early. One in five report significant financial strain. Family caregivers over 50 who leave the work force lose, on average, [more than \\$300,000](#) in wages and benefits over their lifetimes.

Even worse, perhaps, is the physical and emotional toll of extended caregiving. Family caregivers are more likely to experience negative health effects like anxiety, depression and chronic disease. [One study](#) found that those who experienced mental or emotional stress while caring for a disabled spouse were 63 percent more likely to die within four years than noncaregivers who were also tracked. [Another study](#) found that long-term caregivers have disrupted immune systems even three years after their caregiving roles have ended. And caregivers of patients with long I.C.U. stays have [high levels of depressive symptoms](#) that can last for more than a year.

As overworked and underappreciated as family caregivers are, health systems, under pressure to reduce costs, increasingly rely on them to manage illness at home.

There's more we medical professionals can do to improve the way we engage, support and educate them. Family caregivers aren't always clearly listed in the medical record, and even when they are, we often fail to include them in important decisions about a patient's treatment plan — despite expecting them to carry out that plan at home. We assume they're able to perform complex medical tasks — administering injections, changing catheters, dressing wounds, starting tube feeds — but fewer [than half](#) of family caregivers receive the training to perform them.

The Academies' report highlights several measures that could help. First, simply identify caregivers, assess their abilities and anticipate challenges they're likely to encounter. The United Hospital Fund has developed a [tool](#) to understand caregivers' existing home or work duties, as well as what training they'll need to perform new caregiving tasks and any concerns they have about the treatment plan.

Having counseling and support services available to caregivers, as well as [respite programs](#) to temporarily relieve them of their responsibilities, could also help. And clinicians could be trained in how best to educate family caregivers, and to better meet their emotional and physical needs. A nurse might demonstrate how to turn a patient in bed without risking back strain. Or the right way to deliver an insulin injection — how to pinch the skin, what angle to insert the needle — and what signs to look out for if blood sugar levels get too low.

Policy makers can help caregivers, too. [More than 30 states](#) have passed versions of the [Caregiver Advise, Record, Enable \(CARE\) Act](#). The act requires hospitals to identify family caregivers, inform them when patients are being discharged, and provide them with basic education on the tasks they'll be expected to perform. [Other policy changes](#) might strengthen financial support for caregivers by increasing the amount of available paid leave and encouraging employers to offer more flexible work hours.

Caregivers should also feel comfortable speaking up about their needs, and asking for information on services available in their area. Increasingly, there are support groups available to those caring for patients with [Alzheimer's disease](#), [cancer](#) and [other serious illnesses](#). The government's [Eldercare Locator](#) is an online tool that allows older people and their caregivers to identify community organizations that can help with meals, transportation, home care, peer support and caregiving education.

Similarly, local [Area Agencies on Aging](#) can help connect patients and caregivers to the services they need. Employers might consider "time-banking" programs to share leave among employees. And, of course, we can all call to check in on a caregiver, and volunteer our time to give them a break.

If it's a certainty that all of us will experience illness, it's a near-certainty that most of us will care for someone with an illness. But our current conception of patient and disease seems too narrow. It may help to recognize that while patients' needs come first, illness is often a family affair.

For many, caring for a loved one provides tremendous purpose and fulfillment. It can deepen relationships and offer the time and space for connection where it otherwise might not exist. It seems that the goal, then, should not be to reduce family caregiving, but to reduce its burdens.

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