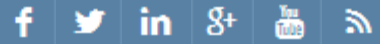


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Better Healthcare Newsletter from Patrick Malone



Dear Jessica,

As Valentine's Day nears, many of us harken back to wedding vows that pledged loyalty and care through richer and poorer, and in sickness and health. Today, tens of millions of Americans live out that commitment every day, caring for a disabled or chronically sick loved one.

As politicians in Washington, D.C., set out to reshape the nation's health system, they're largely ducking a huge challenge: How will we care for each other when we're sick, debilitated, and old? And how will we care for the caregivers?

That crushing burden now falls too silently, more on women than men. Wives, husbands, sons, daughters, relatives and friends of all stripes—they put in exhausting, stressful, and long hours as caregivers. Their labor, with an [estimated value of \\$470 billion annually](#), occurs too often with too little support, and in too many cases without pay. It's harming caregivers' health, well-being,

IN THIS ISSUE

The silent crisis in health: caregiving

Taking better care of our caregivers

High-tech holds caregiving promise

In exurbia, even greater woes

BY THE NUMBERS

43.5 million

Number of Americans providing unpaid caregiving

\$470 billion

Estimated economic value each year of caregivers' unpaid work

\$324,000

Estimated lifetime wages

careers, and finances.

They deserve Valentine bouquets for the time and care they lavish on those in need. But their situation also demands more from all of us—real measures of support, small and large, to ensure that these 40 million Americans, family members, friends, and work colleagues aren't overwhelmed by difficult circumstances. Before we can act, we also need to open our eyes to [America's staggering caregiving crisis](#) and figure out what we might do about it.

The silent crisis in health: caregiving



Here's a [statistical glimpse at America's typical caregiver](#), according to a major 2015 study: She's on average 49 years old. For the last 5.5 years, she has devoted 21 hours a week or more without pay to helping to dress, feed, bathe, shop for, and handle the finances of a relative, likely her mom, who typically is 69 years old. She may live within 20 minutes' driving time. But trying to juggle other responsibilities, including her spouse, children, and a full- or part-time job, is hugely stressful—and it's growing more so.

If this sounds like a tough go, just remember that this is a sketch of the “average” caregiver. One in 10 of them are women 75 or older. They may be devoting 30 unpaid hours or more a week looking after an even older, sicker spouse. They do so alone, and without help. Research shows these older women have carried their heavy burdens for more than five years, and their husbands often have significant health conditions, including Alzheimer's

lost by a woman 50 or older who quits working to care for a loved one

30+ hours

Time per week that women 75 and older devote to unpaid caregiving

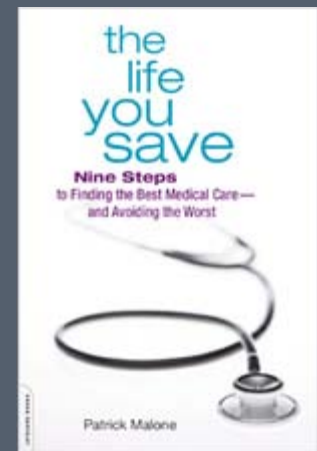
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and severe heart disease.

Younger Americans also are stepping into these challenging roles, with a third of all caregivers now estimated to be millennial men and women ages 18 to 34.

Many scholars and advocates [have warned for some time](#) that the nation's caregiving situation constitutes a crisis, and the [esteemed National Academies of Science, Engineering, and Medicine](#) [has](#) found America's over-reliance on unpaid volunteer caregivers to be unsustainable.

Gloomy demographics

Demographics predict a gloomier future. Americans are living longer but marrying less and having fewer children. There are more single-person households than before. We move around more, and we don't stay near friends and family for a lifetime, as once was the case. American involvement in combat overseas has left [millions of military personnel and their families](#), [all of them relatively young](#), with significant and long-term caregiving challenges.

This all forecasts soaring demand to help us handle myriad daily necessities, [many of them incredibly intimate](#) and challenging to longstanding relationships. But a reliable supply of caregivers is more elusive. Indeed, experts estimate—as the New York Times has reported—that “in 2015, there were seven [potential family caregivers](#) for every person older than 80. But by 2030, this ratio is expected to be four-to-one. By 2050, there will be fewer than three potential caregivers for every older American.”

More bad news? Researchers at the [RAND Corp.](#) [have forecasted that](#), [without some advance in medical science](#), the number of Americans suffering from [dementia—severe cognitive decline](#) due to an array of causes including Alzheimer's, stroke, vascular disease, and Lewy Bodies—will soar from 3.8 million in 2013 to 9.1 million in 2040. The monetary cost of caring for these

the frontlines of medicine for how to become a smarter, healthier patient.



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debilitated people will skyrocket to as much as \$511 billion by 2040. Unless major change occurs, the burden still will be carried mostly by family members or others struggling outside of institutional settings.

Dementia, RAND researchers have noted, [exacts a terrible personal and economic toll on caregivers](#). Their loved ones may not recognize them, and may eventually require exhausting 24-7 supervision and care. Those with dementia also may lose control of bodily functions and act inappropriately, sometimes even violently.

Economic consequences

Caregivers face negative economic consequences. Many wrestle with not only caregiving demands but also keeping up with their own lives and other family members, including spouses and kids. They often must arrive late, leave early, and may need to be absent more or to depart suddenly. Women, especially, may be forced to go to part-time status or even to give up jobs for their caregiving roles. [Research shows that:](#)

"Family caregivers (age 50 and older) who leave the workforce to care for a parent lose, on average, nearly \$304,000 in wages and benefits over their lifetimes. These estimates range from \$283,716 for men to \$324,044 for women. Evidence suggests that assuming the role of caregiver for aging parents in midlife may substantially increase women's risk of living in poverty in old age."

[The caregiving crisis may be contributing to a detectable drag on the economy as a whole](#), experts say, especially as women play an increasingly important role in the labor force but are forced from it by caregiving responsibilities.

Meantime, the stress of shouldering what can seem to be the weight of the world can make life unbearably dark for caregivers. Many say they feel like caregiving pushed them off a cliff with no warning. This isn't something most people plan for. And they

have lost control of their lives. Depression. Fatigue. Anxiety. Worry. These are common, and, sadly, all too little discussed effects that add up and may even shorten their own lives.

Ann Brenoff, a Los Angeles journalist and mother of two active teen-agers, has written with great emotion, courage, and candor about her sudden plunge into around-the-clock caregiving when Vic Johnson, her bear-sized husband, suffered from kidney failure. Fatigued, anxious, and desperate for relief, she wept and begged doctors to keep her beloved longer in the hospital. She did so knowing the family finances would take a big hit from even just a little more time in a noted academic medical center. She captures the loneliness, anger, sleeplessness, conflicting emotions, and desperation that caregivers can experience. Her shame-filled pleas don't end up as she hopes: Her husband gets well enough to be sent to a skilled nursing facility that she finds dismal and unacceptable, leaving her with a bit more rest but much more guilt.

Taking better care of our caregivers



Too many of us Boomers have been downright derelict in preparing for our own care in case we get sick as we grow older. Many of us have too little lifetime savings that will run out too fast, especially if we need medical services that can easily amount to a quarter-million dollars. Americans also haven't made sufficient headway in making long-term care insurance an affordable, widely accessible option.

Now is a critical time to give full attention to political debates about some daunting health care issues. We can't leave it to someone else to worry about what happens to three pillars of our collective means for caring for each other in sickness and age: Social Security, Medicare, and Medicaid. We also need to ensure that partisans truly improve the nation's health care, if, as promised, they repeal and replace the Affordable Care Act, aka Obamacare. These programs represent a huge economic commitment by us all—yes, through that much-demonized function called the federal government.

We can't be bamboozled by slippery language nor lulled to sleep by schemes that pretend to help but end up shredding the already tattered safety net. Watch out when politicians claim that we can spend less and get more services. Ask twice why advocates want us to “put more skin in the game,” meaning many of us will pay more for less, while those who can most afford it skate by. Yes, these programs could gain greater financial stability if we delay or deny benefits to more people. Or could we ask the most wealthy few to contribute more?

Fiscal measures

Caregivers contribute hundreds of billions of dollars in uncompensated labor annually—economic value that is the equivalent of the nation's spending on Medicaid. Policy wonks have proposed ways that we as a nation can recognize and support this invaluable work, with tax credits and other fiscal means. We could help caregivers with greater flexibility on the job, and by prodding officials and the health care system to better support and assist them. We could build and improve badly needed options with paid care.

Some forward-thinking hospitals are recognizing the crucial role that caregivers can play in keeping patients healthy, particularly if they get some attention and help themselves. These institutions are providing caregiver rest areas, trained personnel to help and inform them about what their loved ones are undergoing and

what they will need on discharge. This also benefits the hospitals, which under Obamacare can face stiff penalties for excessive readmissions.

AARP, the nation's largest group representing Americans older than 50, has called on employers to help caregivers with absenteeism, scheduling, telecommuting, long-term retention, and easier changes in work status, going from full- to part-time and back. AARP—which, by the way, offers some excellent caregiving resources worth checking out—says not only employees but also employers benefit from assisting with this life challenge.

What you can do

Individually, as well as collectively in our communities, we also can reach out to better support caregivers. If you do some checking around, you may find your church or social clubs already do so—or you may want to push them to figure how. You also may want to think about your own circle of family and friends: Are there people close to you who may have disappeared from your life because, quietly, they've had to step up as caregivers? You may wish to renew contacts, and do more than give these overwhelmed folks more than air kisses, please. AARP offers some solid counsel on what you can do, including the good advice to be concrete and specific with offers of help: Don't just say you'd be happy to see someone and assist. Instead, suggest something like: I wonder if I could sit with your mom for an hour on Saturday to give you a break? Or: I know my kids will be going to the same event and wondered if I could spare you an extra trip by ferrying yours?

Every little bit helps. You also may find that, as difficult as it may be to see others facing trials, the unstinting love and compassion that caregivers demonstrate every day can be inspiring. It could even deepen your experience of a commercialized holiday like Valentine's Day. Here's hoping you find lots of romance and stay healthy in the days ahead!

High-tech holds caregiving promise



Technology promises to help caregivers with an array of onerous tasks. But will these harried people find new devices sufficiently easy, convenient, cheap, and accessible to take advantage of them?

Some helpful cyber tools already can address some problems. Apps can help caregivers better map and navigate their busy days for maximum efficiency. They can use online calendars to track medical and other appointments easily, and get reminders. They can create online timers for giving medications. They can build reminder lists, so they can track not only drug dispensing but also when groceries or household supplies may be needed.

The rise of cyber commerce also may let caregivers more easily schedule and coordinate doctor, hospital, and other medical services, as well as handle chores like getting groceries or other supplies delivered to their homes. Pharmacies may offer even more robust customer services soon, so caregivers can order medications online and have them delivered, or mailed, or set up an easy pick-up site. The cost of drugs might be dealt with through more automatic billing. This also might

In exurbia, even greater woes



Caregiving's tough enough in American cities. But it can be nightmarish in exurban areas, where medical services are sparse and even endangered, transportation woes can be significant, and caregiving supports and services are few. Issues with distance, demands, and isolation can be crushing for rural caregivers.

Those who need care and those who give it also are older, poorer, and sicker. Younger people, who are fleeing the country for the city, won't be family caregivers. Many rural residents who become caregivers or need their help have worked in physically demanding and stressful jobs, especially in farming and agriculture. This work takes a heavy health toll. It makes it difficult or impossible to take leaves from it or to work part-time in it.

With their prospects dimmed by illness (often chronic and complicated by pain), financial desperation, and depression, rural residents—little wonder—are succumbing to the disease of despair. It's fueling drug and alcohol abuse, and early death, especially through suicide or failure to protect one's health.

A recent public television program focusing on

mean that pharmacies could ping customers to let them know it's refill time.

Although its bugs are still being worked out, telehealth may play a greater role soon to assist patients and caregivers, particularly in remote or underserved areas. This feature, combined with new technologies that make it easier for caregivers to take and record basic health measures like body temperature and blood pressure, may reduce trips for routine check-ups or check-ins. Many insurers are trying to expand their outreach so their customers, including caregivers, can consult with doctors, nurses, or physician assistants to resolve minor medical issues by phone or videoconference.

“Wearable” body-sensing technology also may help health professionals better assist caregivers. Such devices are growing more sophisticated by the day, with imminent prospects that they can offer data on breathing, blood chemistries, infections, and more. They also could provide invaluable insight into patients and their movements or lack thereof. This might help caregivers with loved ones who wander or it might allow distant companions to conduct online checks on the homebound to see if they are safe, active, and even eating properly.

Caregiving's labor-intensive elements also may see help from high-tech machines, including robots that can provide monitoring and a kind of companionship, or that can assist those in need so they can be lifted from a bed and taken around the house, especially

Alzheimer's also deals in depth with the big problems in rural caregiving, examining how New Hampshire finds itself in a crisis with an aging population, declining and scattered medical services, and fewer young people to help older family members and other residents. It's painful TV, illuminating how big, beautiful expanses of rolling countryside also can mean long, hard, lonely, and frequent treks for distant medical services.

The bucolic views in the countryside provide a pointed reminder that it's only a short drive outside the Washington, D.C., Beltway before big swaths of Virginia and Maryland become pastoral and exurban—and residents there struggle with rural caregivers' distinct challenges.

Maryland, in recognition that 30 percent of its population and 80 percent of its lands are rural, has a specialized part of its state health department devoted to rural health, including caregiving. So does Virginia, where, to their credit, two universities—Virginia Tech and UVa—are stepping up to assist with rural health and caregiving gaps and shortfalls. But solutions to rural caregivers' hardships won't come easy or cheap. Technology, (as discussed in another sidebar) may offer some. Rural residents, however, may not have the Internet access or technological facility to take full advantage of these.

More health care and caregiving facilities in rural areas, of course, would be great. The health care system, though, already is thin and highly stressed in rural America, and the GOP proposal to repeal Obamacare could strip

to the bathroom.

Cyber innovations already are helping caregivers and their loved ones break down their isolation, loneliness, depression, and boredom. AARP, for example, operates an active system of [online forums and chatrooms](#) where caregivers can get valuable tips from others in their situation, as well as allowing them a place to vent. Those who are homebound and ailing may find a wider offering than ever of online-delivered distractions, including videoconferencing with friends and family as well as musical, educational, and entertainment shows—and now, [some virtual reality programming that may ease their discomfort and can transport them](#) in vivid new ways to places they have always wanted to go.

[away critical funding that has helped boost it.](#)

If recent presidential actions on immigration also fuel a rise in [xenophobia, this, too, could have ill effects on rural health care](#), which increasingly relies on foreign-born doctors, nurses, and other health care personnel. Rural caregivers already struggle to get their loved ones to the [few hospitals and clinics nearby](#), where the waits are longer, the care may not be the most advanced, and where the [outcomes may be less than optimal](#).

Recent Health Care Blog Posts

Here are some recent posts on our patient safety blog that might interest you.

- [The partisans' planned push for changes to Medicaid could have significant consequences for millions of Americans](#), many of them middle-class, older, disabled, and sick. The Medicaid changes, as various officials like counselor to the president Kellyanne Conway, have described them without detail for now, also could stagger state and local governments' finances, including the already strapped District of Columbia, which might see a half-billion- to billion-dollar hole blown in its budgets.
- Modern medicine [isn't addressing women's distinctive health care needs](#) as optimally as needed, with research further showing it may be time to dial down expectations about breast cancer screening, while heightening physicians' awareness and best practices in eliminating gender biases. Women also may want to keep close tabs on how changes with the Affordable Care Act affect them, and they may be well-served to remind themselves about Texas' sudden surge in maternal deaths and [one of health care's major, gender-based debacles in hormone treatments for females](#).

- Big Pharma has ruthlessly exploited a well-intentioned measure that sought to provide medications to treat patients with rare diseases that might otherwise have been ignored. Drug companies, instead, have manipulated the 1983 Orphan Drug Act to create legally protected monopolies so they can gouge desperate patients with astronomically priced products that already were taken by as many as millions. These findings, part of an investigation by Kaiser Health News, a nonpartisan service focused on health policy issues, were just some of the outrages that surfaced in recent days involving Big Pharma: Two big drug makers have just agreed to pay hundreds of millions in fines for anti-competitive practices or failing to report suspicious transactions, while two pharmacy operations also will fork over millions to settle suits with federal authorities over anti-kickback violations or lax controls.
- Although many of us would like nothing better than to dote on a favorite baby all day long, medical experts have offered some surprising turnarounds and concessions for the new year about what they do and don't know about infant care-giving. They have made a 180-degree reversal on their advice to parents on dealing with the rising problem of peanut allergies, while also suggesting that a familiar product may be more useful than thought to combat a common skin woe. And they have said that 90 percent of the medications given to newborns aren't approved for such uses by the federal Food and Drug Administration.

Meantime, there's been no lack of [action on the Affordable Care Act](#), or the way politicians are [talking about its repeal and replacement](#), or the prospective [new leaders](#) of the government health care system. More information's just a click away.

HERE'S TO A HEALTHY 2017!

Sincerely,

A handwritten signature in black ink that reads "Patrick Malone". The signature is written in a cursive, flowing style.

Patrick Malone

Patrick Malone & Associates

MailChimp.