



HOW CAREGIVING HAS CHANGED SINCE THE PANDEMIC

Experts Share Their Insights

“For some time, the weight of caring was almost all I could see in our relationship. I carried that weight almost invisibly, as is the way of caregivers.”

– KATE WASHINGTON,

author, *Already Toast: Caregiving and Burnout in America*

The weight of caregiving has always been exceptionally heavy for family caregivers, but perhaps no more so than during the pandemic, when social isolation depleted their mental reserves as they provided intensive care within the walls of their home.

Today, **53 million** unpaid and untrained family caregivers provide care for adults and children with complex health needs. As more seniors **age in place** during the pandemic, and as more care for vulnerable children and adults shifts to the home, unpaid family caregivers are highly relied on for their insight into their loved one’s health. Yet they are often **not considered part of the care team**—and this leads to information gaps that make providing care immeasurably harder.

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Meanwhile, as the work of family caregivers becomes more complex and more time-consuming, **just 3 out of 10** have paid help. Part of the reason is that in-home care from specialized aides is expensive, and it’s also hard to come by, given the **shortage of trained caregivers** nationwide, projected to reach **151,000 by 2030**. “Medicare doesn’t offer a full range of long-term care services, and only those who are very low-income or have completely exhausted their savings are eligible for Medicaid,” writes Katherine Harmon Courage of Vox (**“America Isn’t Taking Care of Caregivers,” Aug. 4, 2021**). Those who do qualify for assistance often wait months to be paired with a home care worker as agencies struggle to manage demand and retain talent.

But perhaps the biggest barrier to in-home assistance is the pandemic itself. COVID-19 made family caregivers hesitant to rely on outside support—even from family members—due to fears around exposing

their loved ones to the coronavirus. In this environment, 13% of family caregivers **became caregivers for the first time** during the pandemic. More than one in 10 women say they **gained new caregiving responsibilities** due to COVID-19.

For those in charge of their loved one’s care, the mental and physical toll of caregiving during a pandemic runs deep:

- Nearly half of those who care for a parent say they receive less social support in their role than they did before COVID-19, **one recent study found**. Most of these unpaid, untrained caregivers are Gen X women in the **“Sandwich Generation,”** working parents who are caring for their adult parents and their own children.
- Two out of three unpaid caregivers experienced higher rates of depression, anxiety, fatigue and sleep disturbances than non-caregivers of the same age, a **Centers for Disease Control & Prevention survey (CDC)** found.
- Among adults caring for both children of their own and aging parents, 85% experienced adverse mental health symptoms, and about half said they had struggled with suicidal thoughts in the past month—eight times the rate of non-parents, according to the CDC.
- One in 10 women say they have **quit work due to a pandemic-related reason**, including due to caregiving responsibilities, a Kaiser Family Foundation survey found. Nearly six in 10 **juggle work and caregiving simultaneously**. Some have had to scale back on work responsibilities due to the pandemic.

It’s a scenario that demands attention from healthcare providers, health plans, policymakers and employers, especially as the number of unpaid, untrained family caregivers rises.

Here are three ways the pandemic has changed family caregiving—and how key stakeholders in healthcare, government and the employer sector can make a difference.



1. The pandemic squeezed resources for individuals with complex conditions.

“Even before the pandemic, availability of healthcare resources was limited for major segments of our population,” says Claudia Fine, LCSW, MPH, chief professional officer, eFamilyCare. “Now, patients with chronic illness lack access to many of the types of preventive and routine treatments they need to maintain optimal well-being and functioning because healthcare invests more in addressing complex acute illness rather than chronic care outside of the hospital.” When home-based services do exist—ranging from expert care assistance to social welfare support—“Families have difficulty availing themselves of this support, either because of lack of awareness or due to fear of exposure to the coronavirus,” she says.

The pandemic also revealed the extent to which the healthcare system doesn’t acknowledge the vital role of family caregivers in managing complex conditions. “Caregivers are early warning systems. They know their loved ones, and they know when something is off,” says Beth Bierbower, Host at B-Time Podcast with Beth Bierbower. “Oftentimes, those voices really aren’t heard.”

Meanwhile, family caregivers are tasked with more intensive care from a system that doesn’t provide appropriate training or support. “A lot of people who enter into caregiving unwittingly are pulled into medical tasks that they’ve never dreamed of doing,” says Kate Washington. Washington served as the primary caregiver for her husband as he underwent two years of treatment for a rare form of T-cell lymphoma that included a debilitating stem cell transplant. “This is a strong trend that has really grown over the last couple of decades. Today, family caregivers are being asked to perform duties ranging from IV fluid administration to wound care to really complex medical tasks with quite minimal training, all while dealing with significant emotional strain. The knowledge gap for family caregivers is often extreme.”

These challenges come at a time when three out of four caregivers say navigating the healthcare system **has become more difficult**. Further, among family caregivers responsible for their parent’s health needs, most say their parent’s behavior has worsened during the pandemic (68.8%).

What is needed:

- Skill-based training to help caregivers carry out complex care plans, particularly as the healthcare system limits access to in-person chronic care treatment
- Digital tools that keep family caregivers informed and help them understand and act on what matters, from changes in mentation to strategies for increasing mobility or more effectively managing medications
- Virtual access to professional care advisers, social workers or nurses who can answer questions in the moment, helping families avoid unnecessary emergency department visits and reduce care costs

25% reduction in readmission rates when caregivers have the guidance, education and resources.

Research shows that when family caregivers have the guidance, education and resources to make informed care decisions, this **reduces readmission rates for loved ones by 25%** over 90 days (*J Am Geriatr Soc*, August, 2017).

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– **CLAUDIA FINE, LCSW, MPH,**
Chief Professional Officer, eFamilyCare



2. Telehealth provided an entryway into the home for healthcare providers, giving them an inside view of the patient's circumstances and the challenges family caregivers face.

A RAND Corporation study shows 50% of family caregivers have relied on telehealth during the pandemic. These visits gave clinicians critical insight into the comprehensive needs of patients and **facilitated greater collaboration** between healthcare providers and family caregivers.

“Telehealth has opened the eyes of providers. They can actually see, via Zoom or other video technology, the number of special needs the patient has and why a 15-minute doctor’s appointment can take four hours out of their day,” Bierbower says. “They also gain a greater understanding of the risks that patients face in leaving the home—from the risk of a fall to the potential to catch a cold—and how that in-person visit might complicate a patient’s routine.”

Years before the pandemic, a study demonstrated the ways in which remote patient monitoring and consultation could **improve quality of life** for caregivers of heart failure patients. Participants reported significantly lower family caregiver burden, increased mastery of stress levels and enhanced family function.

Today, advancements in telehealth and widespread use of virtual care show proven potential to **boost caregiver resilience, health status and caregiving skills**. Meanwhile, emerging studies indicate that when telehealth is carefully designed and deployed, virtual services can improve outcomes for **stroke survivors**, strengthen **equity in care and chronic condition management** in children, and **address safety needs** social determinants of health.

Yet now that a COVID-19 vaccine is available, Bierbower sees some providers pulling back from telehealth. “They’re saying, ‘No, no, I’m not going to do this anymore. You need to come in,’” she says. “Pulling back from telehealth services would be a detriment to family caregivers as well as those for whom they provide care.”

What is needed:

- Continued reliance on telehealth not just to enhance convenience for people with complex conditions and their caregivers, but also to limit physical risks
- Legislative recognition of the power of telehealth and the need to **keep expanded access to telehealth in place**
- Increased use of remote technologies to monitor conditions of adults and children receiving home-based care
- More robust mechanisms for sharing remote monitoring data with family caregivers as well as providers



Access to their loved one’s patient portal or chart provides an essential starting point for collaboration and communication. For Bierbower, the ability to access her loved one’s healthcare data as it is posted to the patient portal fosters richer discussions with her loved one’s providers. “We see every test that is being taken; we read the doctor’s notes the morning they are inputted. We see everything that is going on,” she says. “Having timely access to that data from a self-service platform gives us greater confidence in the care being provided. It also helps us keep other family members in the loop.”

“I could be on a webinar or on the phone and people don’t even know that tears are coming down my face. I know I’m still traumatized from it.”

– **SABRINA NICHELLE SCOTT**, New York, who is still recovering from caring for and processing the loss of her grandmother during COVID-19, in **an interview with Vox**



3. There is increased societal awareness of the pressures that family caregivers face.

We're beginning to see greater recognition of the emotional toll of caregiving, from studies that examine the effects of caregiving on family caregivers' health to stories of the trauma that family caregivers experience in the often-grueling journey of managing their loved one's care and the need for increased caregiver assistance.

"There's a lot of guilt around caregiving: 'Am I doing enough? Am I doing the right thing? Oh my goodness, I was short-tempered today. I'm a terrible daughter. I'm a terrible, terrible wife,'" Washington says.

Later, when caregiving duties end, caregivers "are left processing a complex, highly individual blend of feelings: grief, relief (both for oneself and on behalf of a suffering loved one) or even exhilaration, guilt or shame," according to Washington.

Research also points to **health disparities** among marginalized populations who are also caregivers. "Caregivers who come from marginalized populations are less likely to have access to the supports that benefit caregivers in more privileged positions, such as better leave and healthcare benefits," according to the Rosalynn Carter Institute (RCI) for Caregivers report *Recalibrating for Caregivers: Recognizing the Public Health Challenge*. "It is incumbent upon our nation—including policymakers, employers, and organizations such as RCI—to advance solutions that address these disparities and create more equity through public health interventions."



What is needed:

- A push toward recognizing caregiver status as **a social determinant of health**, given that caregiver status affects health outcomes, especially for vulnerable populations
- **Efforts by employers and policymakers** to ease the pressures on family caregivers by establishing caregiving-friendly services and environments
- Mechanisms for providing emotional support, whether through healthcare providers (e.g., caregiver peer groups), health plans (e.g., mental health resources for caregivers), or employers (such as by **grouping PTO programs into a single category of leave**)
- Greater recognition among providers and health plans of family caregivers' value—and increased involvement of family caregivers in care consultation and decision-making

"We have to recognize that emotional support is really needed for the caregiver and their loved one," Washington says. "If the caregiver is not in a good place, they are not going to be as effective in their caregiving role."

"Oftentimes, employees are uncomfortable sharing—even with their immediate supervisor—that there's a problem [managing caregiving duties and work] for fear that they'll be watched more closely; that their performance will be harmed."

– **BETH BIERBOWER**,
Host at B-Time Podcast
with Beth Bierbower

Protecting Caregivers from Burnout

Home is meant to be a place of respite. Now, as more family members take on the role of family caregiver, “Home has become a medical operation,” Washington says. For family caregivers to remain a vital resource, healthcare must recognize their value by including them in care team discussions, providing skill-based training to help them perform complex tasks with competence, and connecting them with digital tools that help them act on what matters. Further, policymakers and employers must develop thoughtful approaches to enhancing access to services that could bolster family caregivers’ resilience while improving outcomes for those in their care. “People want to take care of their family members, but we have to help them,” Fine says.



LISTEN TO THE WEBINAR

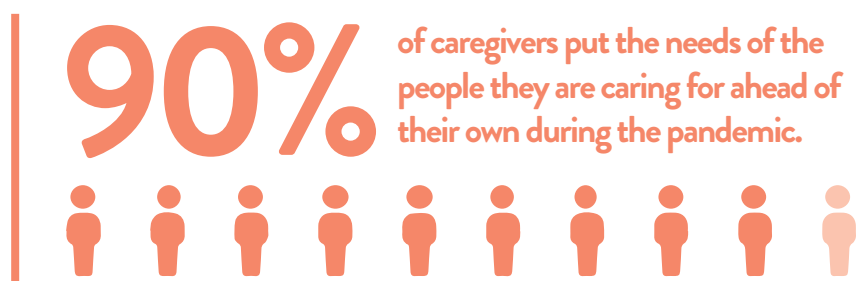
Recently, eFamilyCare presented a webinar on this topic, “How the Pandemic Changed Caregiving,” with input from Claudia Fine, Beth Bierbower and Kate Washington in conjunction with Matter Health.

For more information, visit us [HERE](#).

Where Breakdowns in Caregiving Support Typically Occur

The pandemic compounded existing family caregiving responsibilities for about 40% of those who identified as caregivers before the pandemic, [a Kaiser Family Foundation survey](#) found. Yet even as their care load has increased, most do not receive the support they need to meet their loved ones’ needs—or their own.

More than 90% of caregivers say they have put the needs of the people they are caring for ahead of their own during the pandemic at a time when they also lack access to respite care for themselves. While some states offer counseling or support for unpaid caregivers, coverage is **often spotty and incomplete**.



“**Nearly half of caregivers** are performing complex medical and nursing tasks, like wound care and medication management,” says Terry Fulmer, PhD, RN, FAAN, president of The John A. Hartford Foundation in New York. “Caregivers often provide this care with little or no support and training. This results in caregiver stress and potentially poor outcomes for care recipients, such as rehospitalization.”

While physicians can try to help by referring caregivers to appropriate services in the community, “To the degree that these services are generally not paid for by Medicare—and not substantially by Medicaid, in most states—most care is not organized,” says Howard Fillit, MD, clinical professor of geriatric medicine, palliative care and neuroscience, The Icahn School of Medicine at Mount Sinai.

Further, family caregivers often feel invisible. They may not identify as caregivers, and health systems and service providers often fail to include caregivers as part of the care team. This occurs even as caregivers devote not just their time to their loved ones’ well-being, but also their personal finances, with average out-of-pocket costs of **\$7,242 per year**.

As a result, “Breakdowns occur at every juncture imaginable,” says Bruce Perkins, board member, Global Nephrology Solutions. For example, hospitalizations, transfers to skilled nursing and movement back into home with home care all require careful coordination. When caregivers are not kept informed and involved, “Any misstep creates havoc,” he says.

Creating the Right Types of Assistance for Family Caregivers

There is currently no national strategy that provides guidance on how the public and private sectors should support family caregivers. As recognition of the challenges family caregivers face increases, experts share their views of what the future of family caregiving could look like with the right supports in place.



Howard Fillit, MD

Clinical Professor of Geriatric Medicine, Palliative Care and Neuroscience, The Icahn School of Medicine at Mount Sinai

Founding Executive Director and Chief Science Officer, The Alzheimer's Drug Discovery Foundation

"Family caregivers need expert advice and respite.

They need backup and access to services in the community that help them care for their loved ones and themselves, such as day care. They also need more interface with geriatric social workers.

"With these supports in place, the future state of family caregiving would be a more flexible system that would allow family members continue to provide loved ones with care, to the degree they are able, while still being freed to continue their other commitments, such as childcare and work."



Terry Fulmer, PhD, RN, FAAN

President, The John A. Hartford Foundation

"Caregivers can't do it alone, and they shouldn't be asked to do so. A national strategy, informed by family caregivers themselves, advocates, and the best evidence available, is needed and forthcoming thanks to the RAISE Family Caregivers Act and Advisory Council.

"The RAISE Advisory Council delivered initial recommendations to Congress in September 2021, which presents the blueprint for public and private sector actions to recognize, assist, include, support and engage family caregivers. If followed, caregivers would be less stressed, in better physical and mental health, and their care recipients would have better outcomes. Family caregivers would not feel so alone and in a state of, 'What do I do now?' Society would be better off, too.

"For example, support that helps people remain at home—which is often what matters most to many older adults and people with disabilities—delays or avoids hospital or nursing home placement. It also saves money for families and the government. Paid family leave for working family caregivers and improving wages for home care and other direct care workers are two examples of recommendations that should be implemented."

"Many family caregivers are adult children who are balancing their jobs, their children, their primary family duties, and the additional role of being a caregiver for a parent, adult relative or friend. The amount of stress is almost unimaginable. In addition to the incredible emotional toll, they are tasked with navigating the healthcare system, the social services system and, in many cases, the legal system without sufficient knowledge. Finding third-party help is difficult and, in the case of supportive personal care, almost nonexistent."

– **BRUCE PERKINS,**
Board Member, Global
Nephrology Solutions



Jason Karlawish, MD

Senior Fellow, The Penn Program for Precision Medicine for the Brain, University of Pennsylvania

“Support would address needs along the continuum of disabilities—specifically, problems caused by disabling cognitive impairments from diseases such as Alzheimer’s disease or Lewy Body Disease. People with cognitive impairments need help putting together a day that is safe, social, and engaged. This is where the caregiver steps in as both doer and decider. They are a kind of wheelchair for the disabled mind.

“To do this morally complex work, caregivers need training, education, advice and guidance. They need access to services such as transportation, assistance with meals, housekeeping and visits with clinicians that accommodate them and coordinate care across the many clinicians a patient often sees.”



Eric Rackow, MD

Executive Chairman and Co-Founder, eFamilyCare

“There’s no question that care management is an important and very effective method of helping patients and caregivers, but there is only so much time that care managers can spend with a patient or their family, especially if they have a caseload of 100 to 200 individual patients. What is needed is supplemental support that ensures care plans are followed, medications are adhered to, screenings take place on schedule and questions are answered quickly.

“At eFamilyCare, we believe virtual coaching of family caregivers on caring for their chronically ill loved ones is key. It’s an approach that is proven to reduce unnecessary hospitalizations by 51% by helping family caregivers understand and act on what matters, manage medications, improve their loved one’s mobility and more effectively navigate changes in mentation.”



Jay S. Weinstein, MD, MBA

Chief Clinical Officer, eFamilyCare

Assistant Professor of Medicine, Zucker School of Medicine at Hofstra/Northwell

Co-Medical Director, Primary Care Practice Northwell Health

“The first step is recognizing the importance of caregiving and the challenges that family caregivers face. As a society, we’re seeing signs that this shift is taking place. Now, there is increasing excitement around the potential of digital technology to support family caregivers and help reduce the stress they face.

“So often, family caregivers are thrust into this role without any training. As Baby Boomers age, we’re going to see these scenarios more and more. By providing high-touch support, digitally, from skilled professionals, we can help family caregivers with early detection of medical problems that could turn into serious health issues if left unchecked.

“Our research shows that 92% of family caregivers want to receive virtual advice and support. At eFamilyCare, we’re educating family caregivers on how to become the eyes and ears for the health system—and it’s changing outcomes for patients and their families.”