

Informal caregiving: The unseen obligations and opportunity

Scott Cohen, MPH
Barbara Culley, NHA, MPA
Nicole Gaspar, FSA, MAAA
Christin Kuretich, BS

Introduction

Caregiving is a term that often conjures images of heroic nurses and kindhearted hospital staff, or home health aides and hospice workers in scrubs helping the elderly through their late stages of life.

A less commonly identified picture is that of the informal caregiver, ducking into an empty conference room to take a call from their loved one or frantically running out the door to tend to an emergency.

Today, it is estimated that there are 53 million informal, unpaid caregivers in the United States.¹ The recent COVID-19 pandemic drew greater attention to the fact that informal caregiving can be a burden on the mental and physical health of individuals. Caregiving often extends beyond the traditional idea of caring for elderly relatives. It could be a spouse on disability due to an injury or illness; a special-needs child; or even a neighbor with no family available who needs extra care and attention with activities of daily living (ADLs) such as bathing and dressing, and other supportive services such as laundry, bill paying, and transportation.

For employers thinking about how to effectively manage benefits and provide support for their employees, it's prudent to consider how informal caregiving may impact employee wellness and productivity. Stress can lead to burnout, which can result in presenteeism and absenteeism, and make it difficult to maintain full-time employment. The cost of caregiver burnout from an employer perspective is difficult to estimate.

There are a growing number of solutions that address caregiver support and introduce resources and concierge services where they have not existed in the past. Additionally, Milliman has done a considerable amount of work with existing long-term care insurers using predictive analytics and claimant data to identify high-risk policyholders before they reach severe stages of long-term care (LTC) need.² This paper will discuss the challenges that exist today for informal caregivers and explore different solutions for the caregiving population that may have a meaningful impact on improving the caregiving experience for all parties involved.

Background

Burnout happens when there is a high workload and a lack of resources leading to decreasing motivation.³ When it comes to informal caregivers who are also employed, burnout can be experienced at both ends of the spectrum—in the caregiving situation as well as with full-time work.

Informal caregiving may result from a variety of causes including lack of financial resources to pay for formal care as well as a desire by the informal caregiver to provide direct caregiving support. While long-term care insurance policies have long been available, procurement of these policies is low and generally declining for a variety of reasons, including skepticism that the policy will ever be needed (see the data section below for additional reasons). The low uptake of LTC policies, in turn, has led to carriers offering fewer options for purchase and increasing premiums to match risk. Rising premiums may result in policyholders dropping their policies or not purchasing in the first place.

¹ AARP (June 17, 2020). New Study Reveals Number of Unpaid Caregivers in America Grew by 9.5 Million in Five Years to Total 53 Million. Press release. Retrieved September 28, 2022, from <https://press.aarp.org/2020-6-17-New-Study-Reveals-Unpaid-Caregivers-in-America-Grew-By-9-Million-to-53-Million>.

² See <https://www.milliman.com/en/products/LARA>.

³ Demerouti, E. et al. (November 3, 2021). New directions in burnout research. *European Journal of Work and Organizational Psychology*. Retrieved September 28, 2022, from <https://www.tandfonline.com/doi/full/10.1080/1359432X.2021.1979962>.

There are also hybrid products (e.g., whole life or universal life with LTC riders), but they are not pervasive in the market either.⁴ Buyers are more likely to consider purchasing a policy when they begin to have LTC needs, but if buyers wait until they already have LTC needs, they may not be able to find a carrier willing to write a policy. With this limitation on insurance coverage, along with a lack of ability to predict what long-term care needs might look like, many people end up reaching a point of needing care without the resources in place to obtain it, which, in turn, causes the need for an informal caregiver.

Financially, long-term care needs generally follow one of two paths. The first is that the individual has enough funds to cover the cost of care, which provides them with more (and often better) options, but the ongoing expense of long-term care depletes assets. Another possible scenario is that the individual does not have adequate savings to pay for care, and they qualify for Medicaid. Medicaid has provided a key source of funding for LTC needs, but the eligibility and setup process is often complex, and typically limits the options (i.e., limited facilities, limited providers, and there must be a designated Medicaid bed available, which can mean a waiting list in some instances).

The emotional part of caregiving cannot be overstated. Although not a scientific study, a recent internal Milliman study of our own employees (n=325) revealed that a substantial segment of the employee population was experiencing or had previously gone through a caregiving journey. Some expressed that, as the only local family member, all caregiving responsibilities fell on them. While they felt it was an honor to care for a family member or friend (care recipient), some also expressed bitterness and frustration at the imbalance of help. Others shared their confusion in navigating the care decision process and the difficulty in understanding the resources available and how to access them. Fifty-four percent of those who participated in the survey but had not yet experienced a caregiving role expressed anxiety and fear of the potential future challenge and uncertainty of how it would unfold.

A recent study done by the National Business Group on Health (NBGH) revealed the downstream impact of caregiving on informal caregivers. According to the NBGH survey, 88% of caregivers reported that their responsibilities had a negative impact on their personal health and well-being.⁵ Among other impacts, caregivers:

- Were twice as likely to develop chronic illness
- Were twice as likely to develop depression
- Spent \$7,000 of their own money annually on caregiving expenses

Additionally:

- 92% reported that caregiving impacted their stress levels, with 48% saying “a lot”
- 49% reported exhaustion
- 27% reported stress on their marriage or relationships
- 25% reported missing their own doctor’s appointments
- 16% reported that not covering what was wanted or needed caused additional stress

“Caregiving sneaks up on you. I did not see myself as a caregiver until recently. My husband and I started by helping my mom with yard care, then gradually added weekly grocery shopping, paying bills, and other tasks. We love her, so never see this as a burden, but there are real demands on time, energy, and resources. Everything gets juggled to stay in balance. I worry about what happens if something hinders me from helping—it is always in the back of my mind.”

Milliman employee

“For me, the stress of caregiving is often not the care itself, but the constant build of anxiety that goes along with it. What no one ever tells you about this experience is that you cannot map it out; everyone’s journey is different, and that in and of itself is unsettling. You put parts of your life on hold based on what ‘might’ happen, and then even if it doesn’t happen, you’re still waiting to take the exhale and move forward. And then you feel guilty for wanting to move forward.”

Milliman employee

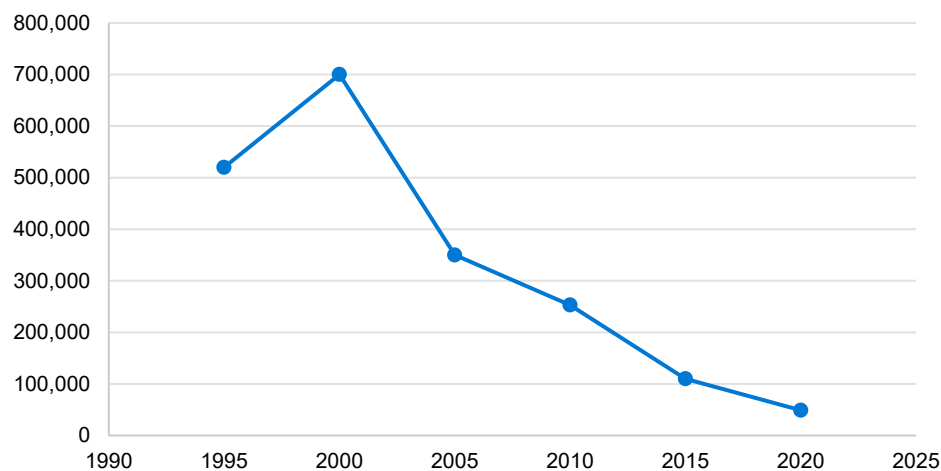
⁴ Eaton, R., Mehilos, B.G., Bahlinger, D. et al. (January 21, 2022). Milliman 2021 Worksite Life Survey. Milliman Insight. Retrieved September 28, 2022, from <https://us.milliman.com/en/insight/milliman-2021-worksite-life-survey>.

⁵ NBGH. Infographic: The Impact of Caregiving on Work. Retrieved September 28, 2022, from https://www.ahtins.com/wp-content/uploads/2019/11/The_Impact_of_Caregiving_on_Work_Infographic-5.pdf.

Data illustrates the growing need for LTC support

It is estimated that nearly 70% of the U.S. population age 65 and older will need some type of long-term care (LTC) support.⁶ Despite the likelihood of needing LTC services, in the United States, less than 6% of people age 50 and over have a LTC insurance policy.⁷ The purchase of traditional LTC insurance has declined significantly over time, as shown in Figure 1.⁸

FIGURE 1: LTC INSURANCE 1995-2020 (AALTCI.ORG)



Some impediments to LTC insurance procurement may include:

- Denial that the need or disability will occur
- Uncertainty about when and what to purchase
- Concerns that coverage is cost-prohibitive
- Misperception that long-term care is covered by Medicare
- Expectations or hope that a family member will provide assistance

As noted, a frequent evolution of this situation is that family members and/or friends step in to provide caregiving and support services. These informal and typically unpaid caregivers may provide a significant amount of the support and services needed for family and friends coping with the challenges of disease, injury, and/or aging. An AARP report estimates that in 2017 approximately 41 million family caregivers spent 34 billion hours caregiving, providing \$470 billion in value of care.⁹ The same report showed that about 60% of caregivers are working and subsequently struggling to find balance between the two priorities.¹⁰

⁶ LongTermCare.gov. How Much Care Will You Need? Retrieved September 28, 2022, from <https://acl.gov/ltc/basic-needs/how-much-care-will-you-need#:~:text=Someone%20turning%20age%2065%20today,for%20longer%20than%205%20years.>

⁷ See <https://aspe.hhs.gov/sites/default/files/private/pdf/265126/LTSSOIAmRB.pdf>

⁸ Long-Term Care Insurance New Policy Sales, Retrieved January 13, 2023, from [2021 long-term care insurance statistics data facts \(aaltci.org\)](https://aaltci.org).

⁹ Reinhard, S., Friss Feinberg, L., Houser, A., Choula, R., & Evans, M. (November 14, 2019). Valuing the Invaluable 2019 Update: Charting a Path Forward. AARP Public Policy Institute. Retrieved September 28, 2022, from https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html?cmp=RDRCT-VALUN_JUN23_015.

¹⁰ Ibid.

The Centers for Disease Control and Prevention (CDC) defines caregiving as providing “care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis.”¹¹ As the person receiving care typically progresses in dependency, the demand on the caregiver generally increases over time. When the caregiver is also employed, the stress and tension between the demands of each role can become challenging, potentially impacting the caregiver, their family, the care recipient, and the caregiver’s employer. An internal Milliman employee survey in 2022 resulted in data indicating an issue among employees.

The Milliman survey (n=325) provides indications that informal caregiving is an issue impacting nearly half (46%) of the employee sample, as shown in Figure 2. Similarly, a 2013 Pew Research survey showed 36% of all U.S. adults stated they had provided informal care to a friend or relative in the prior year, increasing from 27% in 2010.¹² With the oldest Baby Boomers nearing 80 years old it is reasonable to expect increased frequency of informal caregiving.

For employees who indicated in the Milliman survey that they provide or have provided caregiving, when asked if caregiving created an impact to their employment, 72% indicated at least an occasional impact to work. The employment impact was evaluated by the required amount of time taken off work to meet obligations. This impact ranges from one or two times monthly (resulting in some added stress) to consistent and often (resulting in burnout), with distribution as shown in Figure 3.

A “2017 Family Caregiver Journey” report (n=2,767) showed that 38% of those surveyed spent more than 30 hours per week on caregiving.¹³ Nearly 70% reported that caregiving responsibilities have had a negative impact on their work, e.g., they arrive late or leave early. The Rosalynn Carter Institute for Caregivers 2021 survey (n=1,309) found that employees with caregiving responsibilities reported:¹⁴

- Leaving work early/unexpectedly (73%)
- Taking one day off (70%)
- Not taking on added work projects/duties (68%)
- Perceiving their quality or timeliness of work as suffering (60%)
- Taking two or more sequential days off (59%)
- Losing income due to missed work (52%)

FIGURE 2: ANTICIPATED CAREGIVER SUPPORT

Question: Do You/Your Family Provide Custodial or Health-Related Support to a Family Member or Friend?

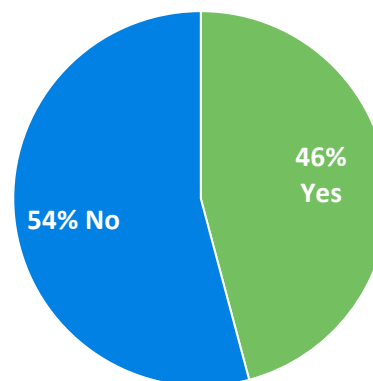
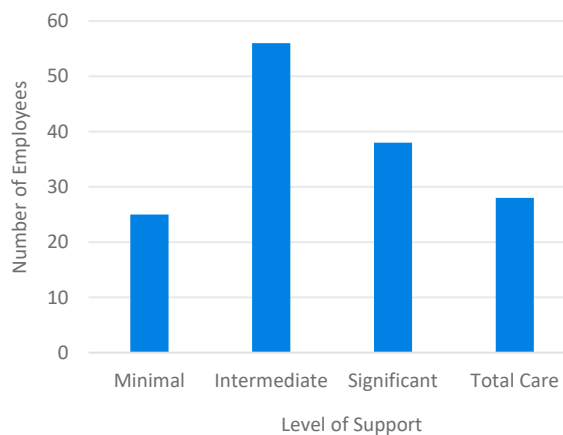


FIGURE 3: LEVEL OF CAREGIVING SUPPORT

Question: What level of caregiving support do you/did you provide?



¹¹ CDC. Alzheimer's Disease and Healthy Aging: Caregiving. Retrieved September 28, 2022, from <https://www.cdc.gov/aging/caregiving/index.htm>.

¹² Desilver, D. (July 18, 2013). As population ages, more Americans becoming caregivers. Pew Research Center. Retrieved September 28, 2022, from <https://www.pewresearch.org/fact-tank/2013/07/18/as-population-ages-more-americans-becoming-caregivers/>.

¹³ Kal, J. Companies that include caregiver support in their employee benefits packages. Monster. Retrieved September 28, 2022, from <https://www.monster.com/career-advice/article/caregiver-support-employee-benefits-1117>.

¹⁴ Harrington, E. & McInturff, B. (September 28, 2021). Working While Caring: A National Survey of Caregiver Stress in the U.S. Workforce. Retrieved September 28, 2022, from <https://www.rosalynncarter.org/wp-content/uploads/2021/09/210140-RCI-National-Surveys-Executive-Summary-Update-9.22.21.pdf>.

Milliman's own survey indicates that there is a potential need for employers to identify the need and support employees who are dealing with caregiving responsibilities. Milliman survey participants were asked if they anticipate future caregiving, and 75% indicated they do expect to provide caregiving, or they may have caregiving requirements in the future. Only 25% indicated they did not anticipate any future caregiving demands.

Caregivers can experience higher levels of depression and physical health problems.¹⁵ Data also show individual differences in the experience of caregiving, with some experiencing negative stress impact, others reporting positive experiences in providing care for others, and some caregivers having both positive and negative experiences in caregiving simultaneously. Women and older adult caregivers appear to be more vulnerable to stress, which can lead to neglect of their own health.¹⁶ While some people can cope with caregiving successfully, the stress of caregiving can worsen due to financial impacts of caregiving and/or the degree of illness of the care recipient, a lack of caregiving skills, and little support or resources for the caregiver. The CDC notes that informal caregiving has been associated with depression, anxiety, higher use of psychoactive medications, worsened self-reported physical health, compromised immune function, and increased risk of early death.¹⁷ For the working caregiver, balancing job requirements with caregiving can be an additional significant stressor. A Blue Cross Blue Shield study showed a 26% greater impact of health conditions on overall health for caregivers, and differences in impact to health by age and ethnicity.¹⁸ The study showed 57% of caregivers reported significant stress, anxiety, or depression. A 2011 poll showed employed caregivers with a physical health index score of 77.4 as compared to a non-caregivers' score of 83.0, with greater likelihood of higher blood pressure and recurring pain.¹⁹

While some employers seek to find options to support their staff beyond the federal requirements of the Family Medical Leave Act (FMLA), a Harvard Business School study showed that only 24% of employers recognized the impact of caregiving on their employees' performance, while 80% of employees who provide caregiving stated their awareness of the impact on their productivity.²⁰ A 2018 Society for Human Resources Management (SHRM) employee benefits survey showed only 10% of employers provide elder care referral services for employees and 2% provide backup elder care as a benefit.²¹

If caregivers who are employed have increasing demands and impacts to personal health, strategies to cope with the competing demands may include use of FMLA benefits, absenteeism, resignation, reduction to part-time, change in employer to better align with caregiving requirements, or the continued tension of juggling priorities.

Considering options to support caregivers in the workplace

It can be overwhelming to read the statistics and viewpoints shared above and consider that the caregiving issue has been growing for quite some time and relief is not in sight. In fact, by 2035 those over the age of 65 will outnumber those under age 18 for the first time in U.S. history.²² There is an opportunity to assess the problem and provide help. For some employers, "analysis paralysis" may take place, where it's difficult to identify the right solution for most people so, instead, no steps are taken. Employers focused on getting it right may find themselves struggling to decide what "right" means. What is clear from the research is that there is not just one way that caregiving is experienced or provided, and the impact on those involved is just as diverse as the scenarios under which it takes place.

¹⁵ American Psychological Association. Mental and Physical Health Effects of Family Caregiving. Retrieved September 28, 2022, from <https://www.apa.org/pi/about/publications/caregivers/faq/health-effects>.

¹⁶ Ibid.

¹⁷ CDC, Alzheimer's Disease and Healthy Aging: Caregiving, op cit.

¹⁸ BlueCross Blue Shield (September 9, 2020). The Impact of Caregiving on Mental and Physical Health. Retrieved September 28, 2022, from <https://www.bcbs.com/the-health-of-america/reports/the-impact-of-caregiving-on-mental-and-physical-health>.

¹⁹ Witters, D. (February 4, 2011). In U.S., Caregivers Suffer From Poorer Physical Health. Gallup. Retrieved September 28, 2022, from <https://news.gallup.com/poll/145940/Caregivers-Suffer-Poorer-Physical-Health.aspx>.

²⁰ Harvard Business School (January 16, 2019). New Research from HBS Prof: Growing Caregiving Crisis Hurting Firm Profitability, Employee Productivity. Press release. Retrieved September 28, 2022, from <https://www.hbs.edu/news/releases/Pages/growing-caregiving-crisis.aspx>.

²¹ Healy, D. (February 18, 2020). Bridging the caregiver benefits gap for employees. ALM BenefitsPRO. Retrieved September 28, 2022, from <https://www.benefitspro.com/2020/02/18/bridging-the-caregiver-benefits-gap-for-employees/?slreturn=20220828051358>.

²² Wilson, R. (March 15, 2018). Older Americans will outnumber youths in just 17 years. The Hill. Retrieved September 28, 2022, from <https://thehill.com/homenews/state-watch/378559-older-americans-will-outnumber-youths-in-just-17-years/>.

There are many resources and programs in place today for caregiver support, but this is an emerging field of research and health. Below are some caregiver support solutions that exist today, and some discussion as to where they might evolve in the future.

CAREGIVER SUPPORT

Before we detail the options, it's important to define caregiver support as it relates to what employers can provide. Caregiver support from employers may be broadly classified as follows:

- **Workplace flexibility and accommodations:** Flexible schedule, work from home, job shares, unpaid leave, etc. According to survey by the Rosalyn Carter Institute for Caregivers, about half of employers offer flexible scheduling or unpaid leave.
- **Financial assistance:** Employer-funded paid leave programs, flexible spending accounts (FSAs), and dependent care FSAs (DCFSAs). There are also products in development today that look and feel similar to the supplemental benefits available on a voluntary basis at the worksite but provide cash benefits for a caregiver when the caregiver pays for formal services, such as supervised day care at a facility or home visits. The trigger for these products can be based on the significance of the care provided or perhaps the frequency. Some of these products may look like a disability product, funding part of an employee's income; others may take on more of an indemnity look or even lump-sum payments with annual maximums that replenish.
- **Specialized caregiver services:** A recent survey indicated that only 14% of employers offered specialized caregiver services, including case management, backup care, and/or services related to in-home modifications to ensure a safe environment for those under care.

EMERGING PROGRAMS

There is an emerging market of companies that provide concierge service and support for caregivers and their families. These programs are often funded by the employer on a per-employee, per-month (PEPM) basis, or they can be bundled into self-funded medical plans or even contributed to voluntarily by the employee. A full-service caregiver support system would consist of some or all of the following components:

- Monitoring health status of the care recipient—an employee who works outside the physical location of the individual receiving care may want to know of changes in health status, danger, etc. A health status monitor will result in timely notification to a person or organization that is ready to assist.
- Case management support, especially to assist with transitions from injury or illness or deterioration in physical or cognitive ability.
- A menu of additional services such as home-safety evaluations, transport services, and meal delivery, through a network of providers that have been credentialed by a qualified organization, preferably at negotiated rates. Having an online-searchable network of credentialed providers would streamline the acquisition of providers, when necessary.
- Assistance with free or subsidized supportive services in the caregiver's local area or community.
- A web- or app-based platform to connect families and care providers, so there is a central repository for health updates on the care recipient. This can also help coordinate appointments, caregiving duties, and other logistics.
- Counseling or other mental-health support for caregivers.

This market is still evolving, and we expect these companies to grow their offerings based on more data and an enhanced understanding of the caregiver journey. Finding ways to scale support, as well as keeping it relevant and affordable, will be the key to success in this field. Today, benefits like an Employee Assistance Program (EAP) are the closest solution to addressing employee burnout or mental health-related issues, but these programs do not tend to specialize in the caregiving space. In addition to EAP, wellness and support programs and caregiver support programs can be bolted onto an EAP so that employees are aware of this additional layer of support the employer has provided.

EMPLOYER ENGAGEMENT

When thinking about the above solutions, it is vital to ensure employees connect with the available support. So how can employer involvement drive better caregiver support?

- Employers have HR professionals with experience, skills, and access to consultants for the procurement of group benefits, both company-paid and optional benefits.
- Several companies (caregiving support vendors) offer services to the caregiver market; formal procurement processes will result in increased quality and better alignment with employee needs.
- As caregiving support vendors increase the number of covered lives, they will gain increased leverage to negotiate lower service fees and quality guarantees from their provider network.

EMPLOYER STRATEGIES

Employers may want to develop strategies for offering a caregiver-support benefit before implementation.

How will employers support and manage this benefit to ensure they are gaining value not only for their dollars spent, but also for employee retention, productivity, and health? A case management/coaching caregiver support benefit has much in common with other coaching/case management wellness benefits already offered by employers (e.g., condition management).

- A relatively small percentage of employees may need or use a caregiver support benefit on an ongoing basis.
- Access to coaching/case management could be priced on a per-participant, per-month basis, giving employers assurance that they would only pay for employees using the benefit.
- Coaching services would include recommendations for monitoring apps, service providers, etc.
- Limiting the “core” scope to coaching/case management allows companies offering caregiving support vendors to price their services without assuming a large risk of underpricing.
- Employers can estimate the expected cost of providing these benefits by surveying their employees for interest. If the cost is more than expected, employees could be billed for part of the monthly fee. For example, the caregiving support vendor could charge a lower rate to the employer and bill employees for the difference.

EMPLOYER CONSIDERATIONS

One concern employers may have in thinking about implementing these programs is budget. In general, employers and caregiving support vendors can limit their risk of budget overruns by offering a set menu of services that can be reliably priced coupled with on-demand services that would generally be paid by the employee. Here are a few examples where the benefit may have a regular component and/or an on-demand component. Employers can choose how much of the menu they will allow the caregiving support vendor to bill to the employer versus billing the employee directly.

- Health risk monitoring and alerts: Vendors may offer a service to monitor clinical data (e.g., blood sugar, blood pressure) or movement patterns, and combine that with a texting or call service to alert the caregiver to potential issues. This could also be priced on a per-participant, per month pricing model and paid by employee or employer.
- In-person check-ins: Vendors may offer services to check in on the care recipient on demand. This could be driven by monitoring results or it could be scheduled at a regular cadence (e.g., once per week) and could include a meals option. Scheduled visits could be priced on a per-participant, per month basis (and paid by the employer or employee), while on-demand visits could be priced on a per-visit basis and likely paid by the employee (to relieve the employer of monitoring the cost of an ad hoc benefit).
- Home safety evaluations (HSE): Vendors may offer HSEs by qualified providers along with a reference list of local contractors that can implement the recommended changes. The vendor might offer a menu of HSE providers with pricing or may offer the service for a set price from its own team. These expenses could be paid by the employer or employee.
- Transportation to doctor’s appointments, adult daycare, etc.: This would likely be priced on a per-trip basis and borne by the employee.

Monitoring the effectiveness of programs is also not a new challenge for employers. Employers may work with caregiving support vendors to administer baseline surveys about the level of unmet need and how those levels change over time, as well as directly measuring satisfaction from both the employees and care recipients. Engagement with the services can also be evaluated by frequency of use.

Summary

The data shows that there is a high probability that we will all need a caregiver, be a caregiver, or support a caregiver at some point in our lives. About 10,000 people turn 65 every day in the United States.²³ Senior citizens are expected to comprise more than 20% of the population by 2050, with most predicted to need assistance at some point, and most of the population not carrying long-term care insurance to cover the costs of required services.²⁴ There is also an increasing number of employees who are providing critical informal caregiving and support to family members and friends to help fill the insurance gap.

As employees juggle competing priorities, savvy employers with strategic awareness of the quiet but growing stress and demands of caregiving on their workforce can use this information to evolve their company's benefit offerings to include an employee benefits design incorporating caregiver support options, caregiver tools and resources, and programs beyond mandatory FMLA to keep staff healthy and engaged.

Companies have a key opportunity to differentiate themselves by developing thoughtful support for employees providing informal care. Support strategies can be appealing and positively impact recruitment, retention, and support productivity. Milliman can help employers understand options and opportunities to augment their coverage array with key caregiver benefits that support employees, productivity standards, and retention strategies.

²³ U.S. Department of Health & Human Services (April 27, 2022). Aging. Retrieved September 28, 2022, from <https://www.hhs.gov/aging/index.html>.

²⁴ See <https://aspe.hhs.gov/sites/default/files/private/pdf/265126/LTSSOIAmRB.pdf>



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CONTACT

Scott Cohen
scott.cohen@milliman.com

Barbara Culley
barbara.culley@milliman.com

Nicole Gaspar
nicole.gaspar@milliman.com

Christin Kuretich
christin.kuretich@milliman.com