Contents

4  Background and Introduction
6  One in Six: Why the Burden of Caregiving Matters to Employers
8  Supporting Caregivers in the Workplace: Why Make the Investment?
13  Digital Caregiver Tools
14  Return on Investment
15  Challenges to Supporting Caregivers in the Workplace
19  What’s Next
20  Acknowledgements
Background and Introduction: The Burden of Caregiving

In America today, approximately 40 million adults (over 16% of the population) informally provide care for relatives. Demographic shifts—increased life expectancy and a growing older adult population—as well as greater health care costs and shorter hospital stays have led family members and friends to shoulder more and more caregiving responsibilities. These are trends which will likely continue: the older adult population in the U.S. is projected to nearly double in size by 2050 (from 48 million to 88 million), with the fastest growing cohort being those age 80 and older, who tend to have greater physical and cognitive health needs.

While many people have traditionally associated the concept of “caregiving” with care provided by paid home care and nursing staff, the reality is that an increasing range of care-related services are being provided by the children, spouses, and parents—and even neighbors and friends—of those individuals requiring care. These services run the gamut and include tasks like grocery shopping, preparing meals and providing transportation, to medication management and assisting a relative in getting dressed, using the toilet, and showering. Additionally, more than half of all family caregivers engage in skilled medical/nursing tasks which can include giving injections, providing tube feedings and overseeing catheter and colostomy care.

And yet despite this reality, many people in the role of caregiver don’t view themselves as such. They are of the belief that caring for a relative or friend “is just what you do” and that they should “take care of their own.” Many caregivers don’t talk openly about this aspect of their lives, not only because they don’t always self-identify as a caregiver, but for those in the workplace, there is a concern that such a disclosure could have a negative impact on their career.

This means that beyond the sheer exhaustion from juggling caregiving with other obligations, caregivers often feel a sense of isolation and loneliness, two emotional

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2. Caregiving in the U.S. (2015), National Alliance for Caregiving and AARP
states that are correlated with increased health risks including a greater probability of coronary heart disease and stroke. Coupled with caregivers’ tendencies to abandon self-care and their own good health behaviors when focusing their attention on providing care to others, it’s no surprise that a higher percentage of caregivers describe their health as “fair or poor” versus the general population (17% to 10%).

Beyond the negative emotional and physical manifestations that may occur while individuals are caregiving, there is often a significant financial impact as well. Family caregivers spend on average $7,000 on out-of-pocket caregiving expenses annually, which is close to 20% of overall income for many Americans. To cover these costs, many are forced to take out loans or dip into savings, creating potential financial instability.

**CHARACTERISTICS OF CAREGIVERS**

- **Caregivers are diverse**—they come from every age, gender, socioeconomic and racial/ethnic group.
- The majority (60%) of caregivers are female but 40% are male, a higher percentage than in the past.
- **25% of caregivers are millennials.**
- On average, caregivers are spending $7,000 in caregiving-related out-of-pocket expenses every year.

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4 Caregiving in the U.S. (2015), National Alliance for Caregiving and AARP

5 Family Caregiving and Out-of-Pocket Costs: 2016 Report, Chuck Rainville, Laura Skufca, Laura Mehegan, AARP Research, November 2016
The complexities of caregiving and its potential impact on the workplace may not yet be on the radar for many employers. But today more than one in six American workers is a caregiver, a number which will surely increase over time. In addition to overall interest and concern about the health and well-being of their employees who are bearing the brunt of caregiving, employers are increasingly aware of the impact on the workplace.

Employers face caregiving-related costs resulting from:

- **Absenteeism.** Caregivers on average miss six to seven days of work each year due to caregiving responsibilities.⁶

- **Lost productivity.** Employees are distracted from work while handling caregiving-related tasks, including dealing with phone calls and crises.

- **Increased healthcare costs.** Caregivers are in poorer health than non-caregiving employees. Caregivers cost their employers an estimated 8% more—or $13.4 billion per year—in healthcare costs.⁷

- **Recruiting and training new staff costs**—there are higher rates of turnover for employees who are caregivers.

It’s been estimated that all these factors combined equal a loss of almost **$38 billion each year** for employers.⁸

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As a result, Northeast Business Group on Health (NEBGH), through its Solutions Center, has embarked on a project in collaboration with AARP to better understand the challenges and opportunities facing employers whose employees serve as caregivers, and identify innovative employer practices that support employees in navigating their caregiving responsibilities while also supporting their health, well-being and productivity. This topic is not new for NEBGH; it has been explored at various times over the last several decades, but there has been a resurgence of interest among employers, driven in part by more media attention and employers' focus on supporting employees' overall well-being. This brief summarizes the research and information gathered by NEBGH’s Solutions Center thus far, including through interviews with NEBGH employer members and via a facilitated employer roundtable co-developed with AARP.

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### Time Spent on Caregiving

Employee caregiving-related costs are not typically a short-term concern for employers.

On average, individuals spend four years in the role of caregiver and 24 hours a week providing caregiving assistance.⁹

<table>
<thead>
<tr>
<th>Hours of Care Provided (per week)</th>
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<tbody>
<tr>
<td>Less than 1 hour</td>
<td>13%</td>
</tr>
<tr>
<td>1 to 8 hours</td>
<td>34%</td>
</tr>
<tr>
<td>9 to 20 hours</td>
<td>22%</td>
</tr>
<tr>
<td>21 to 40 hours</td>
<td>9%</td>
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<tr>
<td>41 or more hours</td>
<td>23%</td>
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</table>

⁹ Caregiving in the U.S. (2015), National Alliance for Caregiving and AARP
Experts as well as some employers point to the potential pay-off of offering benefits and services that make the work/caregiving balance easier to manage.

Incentives for employers to do so include:

- **Maximizing employee productivity.** Obtaining assistance with caregiving helps minimize distractions.

- **Reducing the toll on employees’ own physical and emotional health.** Employees who have support can better focus on taking care of themselves. They’ll be healthier both in the short and long run, which can reduce employer healthcare costs.

- **Promoting a supportive environment.** By providing caregiving benefits, employers can signal their commitment to wellness and well-being.

- **Competing for, and retaining, talent.** Employers who demonstrate that their support for employees extends beyond the workplace will stand out in industries often competing for the best talent.
Employer Approaches to Caregiving Support

The approaches employers can take in supporting employees who are caregivers fall into three major categories:

- **LEAVE POLICIES**
- **DIRECT SUPPORT TO CAREGIVERS**
- **FACILITATED ACCESS TO OUTSIDE CAREGIVING SERVICES**

Here is a sampling within the current landscape of some specific policies and services employers are currently implementing within these categories.
Almost 60% of workers in the US are covered by the Family Medical Leave Act (FMLA), the federal policy that guarantees employees up to 12 weeks of job-protected, unpaid leave. Even among those that are covered, most employees find that they can’t take advantage of FMLA; since the leave is unpaid, it is essentially an unaffordable proposition.

### Fortunately, some employers are allowing employees to blend sick days and personal days, or to broaden the scope of when a sick day can be used.

<table>
<thead>
<tr>
<th>Employer</th>
<th>Description</th>
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<tbody>
<tr>
<td>Goldman Sachs</td>
<td>Provides employees the choice to use sick days not only for when they fall ill, but also to care for someone else in their family who is ill.</td>
</tr>
<tr>
<td>[NEBGH Employer Member]</td>
<td>Has broadened the definition of sick days and personal days so that employees can use both for caregiving needs.</td>
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### Employers are also expanding the amount of paid leave employees can take.

<table>
<thead>
<tr>
<th>Employer</th>
<th>Description</th>
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<tbody>
<tr>
<td>Deloitte</td>
<td>Has been a trailblazer with its generous caregiving leave program. The company offers a paid 16-week family leave program that employees can use for maternity and paternity leave, or for taking care of a sick or disabled parent, spouse, or child.</td>
</tr>
<tr>
<td>Pfizer Inc.</td>
<td>Offers five paid days of caregiver leave annually which can be used by an employee to care for a family member. Additional paid time may be available for other caregiving situations.</td>
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</table>
Direct Support for Caregivers

Some employers are providing in-house support to employees who are caregivers to help them navigate their caregiving responsibilities and feel less isolated.

<table>
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<tr>
<th>Company</th>
<th>Support Services</th>
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<tr>
<td>Prudential</td>
<td>Coaching on site and telephonically on health and well-being, finances and on adult caregiving. In-home adult back-up care is also available at discounted rates for employees, spouses, parents and parents-in-law.</td>
</tr>
<tr>
<td>Northwell Health</td>
<td>Offers an internal Employee Assistance Program (EAP) which provides in-person and telephonic counseling and support.</td>
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<tr>
<td>EY</td>
<td>In addition to offering a variety of vendor resources to address the caregiving needs of its workforce, EY has developed two telephonic peer support groups managed by its internal EAP team. Together, these programs facilitate their career and personal objectives. EY’s caregiver group is designed for colleagues to share resources, information, ideas and their caregiver experiences. EY also has a group to support parents of children with special health needs. In addition to resources and information, this peer group addresses trends in care and parenting of children with special health needs.</td>
</tr>
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Facilitated Access to Support Services

Employers can connect employees with outside services and vendors that provide an added layer of support and assistance.

<table>
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<th>Back-up care</th>
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<tr>
<td>CBS Corporation offers and heavily subsidizes Bright Horizons, a back-up adult care program.</td>
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<table>
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<tr>
<th>Help navigating the system</th>
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<tbody>
<tr>
<td>CBS Corporation makes the Health Advocate program available to employees, their parents, and in-laws. The program provides assistance with Medicare enrollment and claim issues. Employees also have access to a dedicated team at Memorial Sloan Kettering Cancer Center for employees, parents and in-laws to assist them throughout their care.</td>
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<tr>
<th>Second opinions - While not traditionally viewed as a caregiving assistance tool, some employers are offering second opinion services to reduce stress for employees who are concerned about their relatives’ diagnosis and/or treatment plan.</th>
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<tbody>
<tr>
<td>Pfizer Inc. offers expert medical opinions through Pinnacle Care for participants covered under its medical plan; additionally, employees can purchase this for any non-covered family member.</td>
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<tr>
<td>Prudential uses Best Doctors for second opinions and physician referrals. The company asked Best Doctors to expand that benefit for its workforce to include parents and parents-in-law. Since implementing this benefit, 65% of Prudential employees or their relatives using the service received a changed diagnosis, and 35% were given a new treatment plan.</td>
</tr>
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</table>
Digital Caregiver Tools

A variety of new digital platforms exist that are tailored specifically to assist caregivers. Employers can leverage these digital platforms by purchasing and offering them as stand-alone services or by packaging them as an add-on to a health plan’s caregiving benefits. Many of these would likely not be sufficient solutions on their own but could be an effective part of a larger menu of caregiving support services.

Highlights from the current wave of offerings include digital programs that:

- help employees organize all aspects of caregiving including keeping track of doctors’ appointments, medication changes, and home care services;

- offer passive monitoring of relatives at home with wireless sensors that provide alerts if the relative falls or has any changes in eating patterns, or in medication usage;

- provide mobile monitoring of home care staff, with communication tools for on-going connection and dialogue;

- enlist social support networks to share in caregiving tasks; and

- offer a tailored and customized marketplace of paid caregiving staff from which to choose.

As is the case with other forms of digital health, more options with even more sophisticated offerings will likely make their way to the marketplace over the next number of years.
Employers may be interested in measuring whether the introduction or enhancement of caregiver benefits correlates with reductions in absenteeism or presenteeism, or whether there is an effect on healthcare cost trends. However, the advantages of providing employees with the kind of benefits that allow them to be their best at work while feeling genuinely supported in their caregiving role isn’t easily quantifiable by numbers alone.

Many employers are finding that making the business case for incorporating or expanding caregiver benefits will in part rely on the testimonials of employees: using stories as data. This anecdotal data would not be gathered at the exclusion of cost-benefit analysis research, but rather as a way to supplement any empirical data that is being produced by studies. For some employers, particularly those concerned about competing for talent, there may be less of an emphasis on ROI, and more on providing a benefit that will be attractive to prospective and current employees.
Challenges to Supporting Caregivers in the Workplace

The challenges employers face in providing effective support to caregiving employees are not dissimilar to the challenges they face in developing interventions to conditions such as obesity and diabetes. Stigma is a challenge that often surfaces with these conditions, but it is especially similar to that which employers face when attempting to help employees suffering from mental illness, including depression and anxiety. Employees fear their managers will view them as not able to shoulder their responsibilities as effectively as their colleagues, with ramifications for new assignments and promotions. They may resist being labeled as a “caregiver.”
**CHALLENGE:**
Stigma and Lack of Engagement

It’s harder to segment employee/caregivers than employees with a certain medical condition—there is no claims data to analyze. And as noted, employees are not always comfortable identifying themselves as caregivers.

**SOLUTION:**
Higher Impact Employee Communications and Support from the Top Down

One benefits executive explains, “You need to communicate this message to employees: ‘You can’t do it on your own. You are amazing at other things but you need support [with caregiving]—and we can help you.’ The goal is for employees to associate their workplace not only with salary, but also with offering support so they can do their work.”

Employers need to make it known that caregiver support is available — it might not even occur to employees that an employer might have benefits and/or services available, unlike health insurance, which is a given. An executive from a healthcare services agency explained that, “With caregiving—people think very internally. They don’t think ‘what does the employer have for me?’ Caregiver benefits may not even be on their radar.”

Senior executives and first-line managers may be particularly important in creating a culture that normalizes caregiving. If employees know that others more senior to them also deal with this burden, they will feel more comfortable coming forward to discuss their personal situations and what support they need.

Only 56% of caregivers report that their work supervisor is aware of their caregiving responsibilities.10

10 Caregiving in the U.S. (2015), National Alliance for Caregiving and AARP
There are wide variations in the type and scope of policies, benefits and services that employers have implemented to support caregivers in the workplace. Employers are increasingly aware of the need to stay competitive in what some have termed a benefit “arms race,” but there is little guidance or benchmarking available to help them.

**CHALLENGE:** Absence of Best Practices

Employers can look to other employers in their industry to see what is being offered in the way of caregiving support. Employers might also consider surveying employees—or querying existing support groups—to assess what help might be most beneficial.

**SOLUTION:** Survey the Landscape

To expand caregiver benefits, a company needs buy-in from the top. Human resources and benefits managers will have to justify introducing new benefits or enhancing current benefits either in terms of financial savings, or as a means of burnishing the company’s brand and enhancing employee loyalty.

**CHALLENGE:** Getting Buy-In

Some organizations see the value in documenting positive experiences with caregiver benefits as a persuasive argument for enhanced or additional benefits. Another option is providing management with a comparative analysis of what competitors are providing, highlighting those who have had success with expanded caregiver benefits and, for example, associated high rates of retention.

**SOLUTION:** The Power of Persuasive Story-Telling
Employers can understandably hesitate to add yet more vendors to their already vendor-heavy management burden.

**SOLUTION:**
Bundling Multiple Services through a Single Vendor

To avoid jumping through the administrative and legal hoops of bringing new vendors on board and/or managing them, some companies are choosing to supplement contracts with their established vendors to include new caregiver offerings. For example, a company may have a vendor that provides child care, but can also offer adult home care services.
What’s Next?

The employee/caregiver population will continue to grow, and with it, new solutions to support the work-caregiver balance. New innovations will surface in the digital space, and some companies may consider developing their own community hubs through which they will be able to offer assistance and support to employees through help lines, in-house counseling, and on-line resources.

NEBGH’s Solutions Center, in conjunction with AARP, plans to continue to investigate how best to help employers in supporting caregivers. For example, there is interest among NEBGH’s members in some type of clearinghouse or resource portal where they could access information and individuals’ experiences relevant to caregiver benefits and services, and/or provide guidance to their employees.
About NEBGH

Northeast Business Group on Health (NEBGH) is an employer-led coalition of healthcare leaders and other stakeholders that empowers its members to drive excellence in health and achieve the highest value in healthcare delivery and the consumer experience.

About NEBGH's Solutions Center

The Solutions Center is NEBGH’s unique data-gathering and discovery platform for developing initiatives that can “move the needle” when it comes to critical healthcare issues. Focused on employers as a catalyst for change, the Solutions Center’s mission is to identify the most promising, innovative opportunities for improving health outcomes, and create a framework with the potential for transforming results and changing the national dialogue.

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The authors are solely responsible for the conduct the research, analyses, and content of the manuscript.
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- **Louise Fontaine**, Director U.S. Benefits & Immigration, Omnicom Media Group
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- **Shelley Sinclair**, Assistant Director, Health & Welfare, EY
- **Doug Smith**, President, WDSA
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- Michelle Martin, Vice President, HR Specialty Services, CBS Corporation
- Michele Proscia, Director, Employee Benefits, Pfizer
- Bob Stephen, Vice President, Caregiving & Health, AARP
- Michael Weiner, Associate Director, EY Assist, EY
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