SUCCESSFULLY
AGING AND LIVING
IN SAN ANTONIO

An Intitative of the San Antonio Area Foundation
John L. Santikos Charitable Foundation

FINAL REPORT
November 2022

A Balancing Act:
A Guide to Help Organizations Support Employees Who are *Caregivers*

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INTRODUCTION

Ripples from long-emerging demographic and epidemiological shifts—namely the aging of our population—push against every aspect of our lives. Employment is no exception. Today, there are 17.7 million family caregivers to older adults living with chronic and disabling conditions and 53 million family caregivers to persons of any age. Caregivers provide support with daily tasks, such as making healthcare appointments and preparing meals, as well as personal care and medical/nursing tasks. Caregivers in the workforce report how caregiving affects their jobs, including needing to reduce workhours, turn down promotions, and even leave the workforce entirely.[2] Although there are a patchwork of state and federal policies to help families balance employment and care, many caregivers are ineligible for these benefits.[3] Further, while policy protections are important, the slow pace of policy change and varying organizational needs means that workplace solutions to support caregivers must also be undertaken at the organization-level.

In November 2021, Caregiving and Socialization Workgroup from the Successfully Aging and Living in San

6 in 10 of caregivers are employed [2]

Antonio (SALSA) initiative, decided to address how organizations could adapt to better support caregiving employees. To begin this initiative, a sub-workgroup convened a 5-part discussion series with non-profit employers to occur from March through October 2022. The decision to focus on non-profits was made to limit heterogeneity amongst organizations that may have different needs during this first initiative. The goal of this series was to identify challenges employers experience while trying to support caregiving employees, as well as best practices to address these challenges. Through discussion, we wished to help employers to think creatively about their support of their employee caregivers in ways that also meet their organizations' needs.

During the first two events held in March and May 2022, it became readily apparent that workplace policies are inherently tied to workplace and broader societal culture. We learned that while policies may be on the books at many organizations, employees do not readily use these policies. Workers may be fearful that they will be negatively perceived by colleagues and supervisors for using these benefits. Supporting this observation, in one national survey, researchers found that just 55% of eligible employees utilized paid time off.[4] In another, only 53% of employees reported that their supervisor knows about their caregiving role.[2] From these discussions, we learned that to make meaningful change at an organization, leaders would need to begin by addressing organizational culture.

In the third meeting we convened a group of 14 organization leaders for an in-person meeting at the San Antonio Area Foundation. The purpose of this meeting was to build consensus around a pledge that could guide organizations to create more caregiver-supportive workplace environments. Using a nominal group technique, participants brainstormed priorities areas through three rounds of rapid idea generation, followed by discussion to refine and consolidate ideas. The result of this two-hour process was 10 priority items that were circulated and refined.

Today, there are

17.7M

family caregivers caring for older adults living with chronic and disabling conditions.

We hope that organizations, both non-profit and for-profit, will use the resulting pledge to identify how their organizations already support employed caregivers, and also as way to identify action steps to support employees and colleagues who are caregivers.

In this guide, we provide information about each priority item, including examples. We also share stories from actual caregivers, which illustrate the need for better workplace supports. Employers will find a worksheet for organizations to use as they identify specific action steps they will take. At the end of this guide is a list of resources to support these efforts.

We hope you will report back on how these pledges and strategies have helped your organization. **Please contact Kylie Meyer, PhD, at knm77@case.edu or Jane Paccione at jpaccione@saafdn.org to learn more about the SALSA initiative.**

BACKGROUND

Family Caregivers Struggle to Balance Employment and Caregiving

Former first lady Rosalyn Carter once said, "There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers." In the U.S.,there are 53 million family caregivers caring for adults living with an illness or disability.[2] The need for care is expected to increase over the next several decades due to population aging. The population of persons ages 85 and older, who are most likely to require care, is projected to nearly triple from 2020 to 2050.[5] Growth in the older adult population is also expected to increase the prevalence of Alzheimer's Disease and related dementias (ADRD), a condition which requires intense caregiving in its mid-to late-stages due to care recipient cognitive changes. Whereas there are currently 6.2 million persons living with late-onset ADRD in the U.S., this is projected to more than double to 12.7 million by 2050.[6]

These demographic and epidemiological shifts have led to a "new normal," wherein many employees are also family caregivers. Sixty-one percent (61%) of all caregivers are employed, and one in six full- or part-time U.S. workers are caregivers.[2,7] The majority of family caregivers report that caregiving has affected their employment, such as taking time off work to provide care (53%), reducing their paid employment hours (15%), turning down promotions (7%), and even having to end employment entirely (10%).[2] Whether or not employers choose to address it, caregiving often cannot be "left at the door" of the workplace. Employees who provide care often must respond to calls from healthcare providers throughout the day, and may be less focused at work due to unaddressed caregiver stress (i.e., presenteeism).[8]

An Opportunity for Employers

This is not to say that employees who are caregivers are "a problem to be solved" by employers. Caregiving is far too ubiquitous to be considered a problem affecting a small handful of employees. Rather, the need to balance employment and caregiving is a challenge that employers have an opportunity to prepare for and address. Employers may be incentivized to act in the interest of retaining experienced employees, which can render cost savings.[3,9] One estimate by AARP found that employers pay $6.6 billion to replace employers who leave the workforce to provide care, and another $6.3 billion on workplace disruptions.[10] Employers can help employees to manage these disruptions through options such as flex-time an remote work (telecommuting). Another study found that investment in flexible workhours have considerable return on investment (ROI). A report from AARP and the ReACT coalition reported that organizations may experience an ROI between $1.70 and $4.34 for each dollar invested in flextime, and an ROI of between $2.46 and $4.45 for each dollar invested in telecommuting.[11]

Beyond costs, policies that meet that needs of caregiving employees may also attract employees and help organizations to maintain a diverse workplace environment. As emphasized by the Care Can't Wait Coalition, caregiving responsibilities disproportionately affect African Americans, Hispanics, and other persons of color.[12] Seventeen percent (17%) of white employees are caregivers, compared to 21% of Black/African American employees, and 20% of Hispanic employees.[7] We also know that in the LGBTQIA+ community, family often includes "families of choice" rather than relationships defined by birth or law. The few kin roles covered under FMLA thus do not always meet the needs of LGBTQIA+ workers and their families. Better support and non-discrimination of caregivers is especially important to fostering a diverse workforce. Further, "pushing out" caregivers from the workplace because of their care duties is a form a family responsibility discrimination (FRD). Although there is technically no law against FRD specifically in the US, discrimination against employees who provide care may violate other legal statutes such as the Americans with Disabilities Act.[13]

ORGANIZATION PLEDGE TO SUPPORT EMPLOYEES WHO ARE CAREGIVERS: OVERVIEW

Given the dynamics of a changing workforce, the following priorities have beend developed and should be viewed as guiding principles, rather than being prescriptive. It is recognized that every organization is different. Some priorities will be more relevant to some organizations than others. We hope that organizational leaders will consider reviewing these priority areas and selecting 2-3 priorities they would like to focus on during 6- to 12-month period. We have provided ideas for action steps you might take, but there are many others which you may consider that fit your organization. We strongly recommend organizations review their progress and update pledges 1 to 2 times per year. It is also recommended that organizations consider selecting a "champion" to ensure accountability and follow up on action steps throughout the year.

PRIORITIES FOR ORGANIZATIONS TO SUPPORT EMPLOYEES WHO ARE CAREGIVER

01

ACCOMMODATE THE NEED FOR FLEXIBLE WORK SCHEDULES, TO THE EXTENT POSSIBLE BY YOUR ORGANIZATION.

Caregiving can be acute or chronic, depending on the needs of the care recipient. Yet, many current leave policies are designed for care that is temporary, and then relinquished once the care recipient recovers. In an aging society, this is often not the trajectory of care. Caregiving is becoming increasingly chronic and unpredictable, rendering the need for work schedules that can accommodate this uncertainty. Employees and employers will have different needs to consider, and thus it is important that solutions be devised in partnership. It is also important to recognize that not all employees are in jobs that can accommodate remote work or flextime, and thus organizations should consider the extent to which solutions are equitable amongst employees.

ACTION STEPS:

- Allow employees to work remotely for some or all of the work week, when possible, and provide materials and guidance that help these employees to succeed while remote.
    - Invest in technologies and technology training to enable remote work, such as file-sharing systems, meeting platforms, and software.

- Allow employees to adopt a flexible schedule, such as starting their workday early so they may end before the end of the workday OR starting their workday later in the day and leaving later. Employers might also consider "comp time" to make up time.

- Allow employees to discuss their ideas to support a more flexible work schedule, and consider pilot testing a modified schedule for a set time and evaluating how it goes. Employers are encouraged to focus on outcomes, not the schedule: Is the work getting done?

- Provide a 4-day work week option to employees, so they have a day when they can schedule appointments and complete errands for their loved one.

- Enact a policy that allows employees to use their sick time to care for a family member, or pool sick time with other forms of paid time off. Ensure that management knows how to support employees to use leave options.

- Provide an option where other employees may donate leave time, such as sick leave, to a colleague who is providing care.

- Provide time and space for caregivers to manage caregiving matters during the workday, such as a private office area. These matters include calls with the

S.J.P., FEMALE CAREGIVER TO LOVED ONE

"My caregiving journey helped me grow as a humbler person, and it gave me confidence and a sense of purpose in life. It made me think that I can do good for others and share what I have with others. Colleagues and supervisors supported me by letting me be with my loved one at the time needed, and by providing support. They always kept in mind that self-care is needed to continue providing good service to our clients."

healthcare team, ordering prescriptions, and coordinating care with others which cannot be avoided or must be handled during traditional work hours.

- Cross-train employees so that when one employee needs to take time off to provide care, there is someone else who is prepared to manage their job responsibilities.
- Reassure employees who are taking on new responsibilities to cover for another colleague and make sure they feel comfortable with these responsibilities.
- Allow employees to cover for each other for jobs that require shifts, where a caregiver may ask another colleague to cover when they need to provide or another colleague may offer to do so.

L.O., DAUGHTER CARING FOR MOTHER

"Working with individuals willing to be supportive and understanding has made a difference in my caregiving journey. Colleagues and supervisors ensured I could care for my loved one by taking the time to sit down and listen. They also directed me to resources and someone in our agency who has knowledge, as well as access to various programs. I would want employers to know that caregivers in the workplace will have days when they feel drained, and also depressed at times from the lifestyle changes that occurred during the caregiving process, and this should be ok." **L.O., with her mother, left**

02 PRACTICE OPEN COMMUNICATION WITH EMPLOYEES AROUND CAREGIVING ISSUES.

Developing a plan to help employees to balance employment and caregiving begins with communication: employees and employers need to be able to communicate their needs, and come up with solutions together. Communication must be bi-directional to so that everyone is aware of expectations. This also applies to employers who are caregivers where supervision may be disrupted by caregiving responsibilities, such that everyone is aware of what to expect.

ACTION STEPS:

- Integrate questions about caregiving responsibilities during regular meetings with individual employees to provide support.

- Encourage a culture where colleagues support each other, and promote equity by having colleagues "pitch in" to help one another.

- Plan additional team or one-on-one meetings when supervisors or other key persons needs to use leave or other options to balance caregiving, where each party can communicate expectations and resolve questions.

03

BUILD A CULTURE WHERE CAREGIVERS FEEL THEY CAN TALK ABOUT THEIR CAREGIVING.

Hand-in-hand with recommendations to support open communication about caregiving is to ensure employees know this will not backfire on them. Employees should be provided with cues that they are welcome to talk to their colleagues and supervisors about their caregiving role without retaliation or being harmed by negative assumptions about their commitment to employment. On the other hand, employees should also feel comfortable to set boundaries and to not discuss parts of caregiving they do not wish to.

ACTION STEPS:

- Provide visual cues around the office to indicate that that the organization supports employees who are caregivers, such as signs on office doors, bulletin boards, and in break rooms.
    - ○ Consider posting the handout on page 31 of the report "Supporting Caregivers in the Workplace: A Practical Guide for Employers": https://nebgh.org/wp-content/uploads/2017/11/NEBGH-Caregiving_Practical-Guide-FINAL.pdf

- Model open communication and understanding among leadership, such as by talking about one's own caregiving experience, which also shows understanding.

- Educate employees who are not caregivers about the challenges caregivers experience and how this affects work, so as to build a culture of empathy.

- Enable caregivers to signal when they do not wish to talk about

Although often assumed to fall on women,

54%

of employed caregivers are men who also need workplace support. [7]

caregiving, such acknowledging that it is okay say "it's one of those days" and leave it at that.

04 PREVENT DISCRIMINATION AGAINST CAREGIVERS IN THE WORKPLACE.

In a recent survey, 59% of employees agreed with the statement that "Caregivers are perceived to be less committed to their careers than non-caregivers."[4] This statistic alone can shed light on many employees not disclosing their caregiving duties to others, who might assume they are less committed to their employment. Caregivers encounter significant stigma in the workplace that can hinder career aspiration and financial wellbeing. To prevent these attitudes and assumptions from undermining a caregivers' ability to succeed in the workplace, we encourage employers to address and prevent family responsibility discrimination against caregivers.

I.L., DAUGHTER CARING FOR MOTHER

I was given great support when I was taking care of my ill mother before she passed away and that was very helpful to me to know that I could talk to someone about my feelings." **I.L.'s mother, right.**

ACTION STEPS:

- While interviewing for open position and promotion, ensure that all personnel involved in hiring and promotion understand organizational policies about non-discrimination against caregivers and other types of family responsibilities.
- Reassure potential hires that this is an organization that supports family caregivers, such as by describing benefits and supports offered to caregiving employees.
- Include language in job descriptions that encourages caregivers to apply, specifically. Employers might be encouraged to use statements that point to an organization's core values or principles, such as "People who are caring for

a family member, including families of choice, are encouraged to apply." Consider also adding whether reasonable accommodations to support caregivers may be available, such as schedule modifications.

  - Consider visiting the Society for Human Resource Management for guidance: https://www.shrm.org/resourcesandtools/hr-topics/benefits/pages/improving-lives-of-employee-caregivers-makes-business-sense.aspx

- Avoid negatively assessing employment gaps, where an applicant may have been providing caregiving. Employers might ask, "So while you were on this break, how did you keep your skills sharp?" Be open to hearing how skills used as a caregiver also apply to the workplace.

- Integrate caregiving into your organization's diversity, equity and inclusion strategy and activities, including education sessions and meeting agendas.

- During employee evaluations, ensure that supervisors do not negatively appraise loss of productivity that may occur due to caregiving, and account for how life changes may affect performance. Collaborate with employees to set reasonable expectations about what can be accomplished in the workplace while caregiving.

- Ask caregivers what they need, rather than assuming they have "too much on their plate" or will be less committed to their role.

05

ENGAGE IN CONTINUOUS LEADERSHIP TRAINING TO HELP ORGANIZATIONAL LEADERS TO LEARN HOW TO SUPPORT EMPLOYED CAREGIVERS.

While written policies can guide how an organization will respond to support caregiving employees, there are many case-by-case decisions that require a knowledgeable leadership team. Further, as the organization changes, it is important that incoming leaders are knowledgeable about how to support employees who are caregivers. Leadership training may be particularly important given the possibility that those promoted into leadership roles may—though not always—have less exposure to caregiving than other employees. This can occur when caregivers leave the workforce and those workers who are promoted into leadership. A Gallup poll found that the proportion of employees who are caregivers is inversely related to education and income.[7] Topics for leadership training include but are not limited to: how caregiving affects employees, skills to communicate with employees who are caregivers, how to build and sustain an environment that is supportive of caregivers, as well as current organizational, local, state, and federal policies to support employed caregivers.

ACTION STEPS:

- Provide regular training to leadership team member about how caregiving affects employees and company policies available to support caregivers.
    - You can find list of resources to better support and educate employers at the end of this document.
    - This includes training on communication and emotional intelligence, such as active listening and understanding non-verbal cues.

- Show compassion to employees who are experiencing distress and possible grief, understanding the grief is a complex process that may ebb and flow.
- Host group discussions where the leadership team can identify challenges with supporting caregiving employees, and work together to identify solutions.

- Integrate balancing work and caregiving into mentoring discussions with new leadership members, and encourage new members of organizational leadership to raise their questions and concerns.

06

PROVIDE, ON A REGULAR BASIS, CAREGIVER EDUCATION AND DISTRIBUTE RESOURCES.

Caregivers require ongoing learning opportunities as their roles evolve. Common learning needs include: where to find community resources, legal and financial planning, employees' rights as caregivers, and accessing mental health support. Employees who are not current caregivers can also benefit from education, such as to understand how caregiving affects their colleagues and to raise awareness among employees who do not yet recognize themselves as caregivers, but who nevertheless provide care.

ACTION STEPS:

- Send a yearly information email to employees to remind them of the organization's policies to support family caregivers. This is a helpful reminder to current caregivers, and may be new information to employees who recently entered the caregiving role.

- Circulate a list of community resources to family caregivers, including information about who to contact in the organization about caregiving concerns.
    - At the end of this document, you will find a list of resources you can personalize for your organization's needs.

- Identify and support "caregiving mentors" or "champions" who have first-hand experience in this role, and can support other employees through information and emotional support.

- Convene education events such as at staff meetings or lunch-and-learns dedicated to sharing caregiver information. Organizations might consider contacting their local Area Agency on Aging to identify local speakers knowledgeable on these topics.
    - Find your local Area Agency on Aging by using the ElderCare Locator site: https://eldercare.acl.gov/Public/Index.aspx

- A host caregiver support group meeting to enable employees to share information amongst themselves about how to balance employment and caregiving, as well as other topics related to care.

- Integrating modules on caregiving topics, such as organization policies and caregiver rights, into new employee training and current employee refresher training courses.

07

ADVOCATE FOR LOCAL, STATE, AND FEDERAL POLICY CHANGE TO BETTER SUPPORT CAREGIVERS TO BALANCE EMPLOYMENT AND CAREGIVING.

As our society addresses the policy gap that has emerged from slow-moving

C.C. AND A.B., SISTERS CARING FOR MOTHER

"My sister and I both work full time and have very demanding jobs... The journey has been stressful as we balance work and her care. She is now so much better, with receiving the care needed to supervise her medical conditions... My sister and I continue to work and are appreciative of having compassionate supervisors who allow us to take time off to care for our mother. It is through the support of our employers that we continue to work and provide for our own families/households."

policy change in a quickly-changing society. Employers should be a part of this discussion to ensure that policies meet their and their employee's needs.

ACTION STEPS:

- Stay up-to-date on policy initiatives that may better support caregivers.
    - Consider signing up for the Family Caregiver Alliance Policy Digest newsletter: https://www.caregiver.org/about-fca/news-press/caregiving-policy-enewsletter/

- Tell your representatives how such initiatives affect your organization and its employees, such as proposed changes in federal leave programs, paid leave options, and legislation to increase access to caregivers supports and services in the community. You may write a letter or set up a meeting with your representative.

08

EXTEND CURRENT FEDERAL AND STATE POLICIES, SUCH AS THE FAMILY MEDICAL LEAVE ACT.

There are some current laws to help families to balance employment and caregiving, such as the Family Medical Leave Act (FMLA) and paid family leave (PFL) offered in some states. (Texas is not one of the states which requires paid leave.) One limitation of these laws is that definitions of the term "caregiver" and other eligibility criteria may be limited. For example, FMLA criteria currently covers caregivers to a spouse, child, or parent with a serious illness. Some states have extended these kinship criteria to include other kin relationships, such as grandparents and siblings. Although these laws place certain requirements on an employer, there is no reason an employer cannot voluntarily extend eligibility.

> The high cost of paid assistance is one of the most frequently reported reasons for workers leaving the workforce due to care,
>
> cited by **53%** of workers who reported leaving a job to provide care.[4]

ACTION STEPS:

- Extend kinship definitions included under the Family Medical Leave Act to include family relationships such as siblings, grandparents, domestic partners, as well as families of choice.
    - Learn more about FMLA requirements here: https://www.dol.gov/agencies/whd/fmla

- Provide job protection to employees whose service with the organization falls below the 12-month eligibility criteria, such as by offering FMLA benefits or sliding-scale benefits.

- Extend job protection even when your organization does not meet federal requirements, such as organizations with fewer than 50 employees working within a 75-mile radius.

- Support employee financial wellbeing while on leave by offering a paid leave option that is suitable for your organization.

09

OFFER AN EMPLOYEE RESPITE BENEFIT TO ALLOW CAREGIVERS TO TAKE A BREAK FROM CAREGIVING.

Respite care allows a family caregiver to take a break from caregiving, such as by paying a home care agency or another family member to look after their loved one. Respite care may be a one-time event (e.g., to take a weekend away) or done regularly (e.g., once a week). Respite may be an important tool to prevent "presenteeism," wherein worker productivity is negatively affected by pre-occupation with caregiving responsibilities while at work.[8] Many caregivers struggle to access respite care due to the high costs, and limited availability of low-cost options and waivers. The high cost of paid assistance is one of the most frequently reported reasons for workers leaving the workforce due to care, cited by 53% of workers who reported leaving a job to provide care.[4]

ACTION STEPS:

- Provide a respite care benefit, such as an 8-hour monthly voucher or other amount to help caregivers to take a break and engage in self-care.

10

PLAN FOR SUSTAINABILITY BY BUILDING CAREGIVING INTO POLICIES AND PROCEDURES.

Organizations are encouraged to build caregiving into their organization's strategic plans. Caregiving has been called "the new normal" in our society. Organizations who plan for this shift may be better able to adapt to a changing workforce than those who do not. As the workforce evolves due to changing families and care demands, this is an issue that employers will need to reflect upon continuously to meet the needs and expectations of their employees. We recommend that organizations consider the following actions steps.

ACTION STEPS:

- Conduct an assessment of caregivers at your organization, such as through an anonymous survey of employees. Also ask about their current needs and perception of how the organizations meets these needs. Convening a discussion group can also help shed light on current employees needs and perceptions.
    - Consider using the Massachusetts's Employer's Toolkit Assessment Tool: https://macaregivercoalition.org/sites/mtc/files/documents/MeHI/MAEmployersToolkit.pdf
- Review current organizational policies to support employees who are caregivers to see if they do enough to create a culture of care in your workplace, and where gaps may exist.

C. Z. Female Caregiver for Sister

"My sister and only sibling was diagnosed with cancer on Valentine's Day…For once, I was glad about COVID - it had paved the way for me to start working remotely from the town where she lived. But after a few weeks, my sister said that she was lonely much of the day with everyone working… I didn't hesitate and made arrangements to use my paid time off. I assumed I would then go on Family Medical Leave (FMLA), which is unpaid leave for up to 12 work weeks per year. By late April, we discovered none of the chemo the oncologists had tried were helping. The cancer was continuing to spread and grow. My sister was now only 80 pounds and failing. She made the difficult decision of stopping all treatment and going on hospice…What they don't say is that in many places, especially during COVID where workers shortages have been common and extreme, hospice is actually relying on those family and friends to provide 100% of the care…and the one question they couldn't answer was who was going to help us provide hands on care for months. So, a friend and I started our 24-hour shifts… we were all exhausted. My boss at work was always incredibly supportive. When my paid leave was exhausted, she called a meeting with HR to discuss FMLA. They put together the documents and were just about to close the meeting when the HR representative exclaimed, 'I forgot. FMLA doesn't cover siblings. It only covers parents, spouse and children.'… So, I went back to work remotely, caring for my sister and working my 40 hours whenever I could. I am fortunate that I could put together any type of schedule that allowed me to continue to work with pay. Many caregivers don't have that option and can no longer pay their own bills."

- Build supports for caregivers into your strategic plan, and reflect on how this support needs to be updated at least yearly.
- Evaluate the costs of not doing more to support caregivers on the sustainability and performance of your organization, including retention, recruitment, productivity, and workplace satisfaction.

Organization Pledge to Support Employees Who are Caregivers

[Organization name] is committed to supporting our employees and colleagues who are caregivers to a family member living with a chronic illness or disability. We recognize that caregivers are the backbone of the U.S. long-term care system, and provide care at considerable cost to themselves. Caregivers often experience immense challenges in this role that affect their jobs, such as stress and burden and loss of personal time to address their own needs. We also know that caregiving is a normal and expected part of the life course. We strive to create a workplace environment and policies that helps employees to succeed in the workplace and maintain their wellbeing, while also taking care of a family member. We therefore pledge to advance the priority areas listed below to help employees remain—and thrive—in the workforce whilst also providing care. In doing so, we intend to promote a workplace where our caregiving employees can feel fulfilled, valued, and supported.

Under each item we plan to focus on, we describe specific action steps we will take towards this goal over the next 6 months to 1 year, as we realize this organizational change is an ongoing process. (Note: It is recommended that organizations selected 2-3 foci to commit to, and then select others in the future.)

- **Accommodate the need for flexible work schedules, to the extent possible by your organization.**
    - Example: Our organization will review our current work from home policy, and/or develop a remote working policy.
    - ______________________________
    - ______________________________

- **Practice open communication with employees around caregiving issues.**
    - Example: Our organization will have a regular updates on the FMLA at staff meetings.
    - ______________________________
    - ______________________________

- **Build a culture where caregivers feel they can talk about their caregiving.**
    - Example: Our organization will review the SALSA Caregiver toolkit and make available for staff.
    - ______________________________
    - ______________________________

- **Prevent discrimination against caregivers in the workplace.**
    - Example: We will seek out resources to train our team on the issues of caregiving.
    - ______________________________
    - ______________________________

- **Engage in continuous leadership training to help organizational leaders to learn how to support employed caregivers.**
    - Example: Seek speaker on compassion fatigue for potential training session.
    - ______________________________
    - ______________________________

- **Provide, on a regular basis, caregiver education and distribute resources.**
    - Example: Invite local Respite Care Organization to deliver training and resources to staff.
    - ____
    - ____

- **Extend current federal and state policies, such as the Family Medical Leave Act.**
    - Example: Extend Federak guidelines to include families of choice and additional family members (sibling).
    - ____
    - ____

- **Offer an employee respite benefit to allow caregivers to take a break from caregiving.**
    - Example: Research the possibility of offering xx hours of respite support per month.
    - ____
    - ____

- **Plan for sustainability by building caregiving into policies and procedures.**
    - Example: Cross train staff to support operations.
    - ____
    - ____

- **Advocate for local, state, and federal policy change to better support caregivers to balance employment and caregiving.**
    - Example: Draft letter of support for expansion of the FMLA.
    - ____
    - ____

____

By signing this document, we demonstrate our commitment to pursuing these goals in earnest, such as by committing the time and necessary resources to accomplish these action steps. (Recommendation: Signatures may be provided by the leadership team where this issue is most relevant, including directors, board members, and Human Resources. It is important that all relevant parties communicate about completion of this pledge.)

Resources for Family Caregivers ●●●●●

Local Resources for South and Central Texas

- **A Caregiver's Toolkit: What You Need to Know When Caring for Someone.** Caregivers in the San Antonio region are strongly advised to review the Caregiver Toolkit created by SALSA members. This toolkit provides a step-by-step guide to support caregivers. **Link:** https://saafdn.org/wp-content/uploads/2020/09/CAREGIVER-Booklet-1.pdf

- **Caring for the Caregiver at UT Health San Antonio.** Caring for the Caregiver offers caregiver education programs and socialization events. Join for the monthly Essentials of Caregiving lecture series, or the Memory Café social engagement sessions. Programs are offered virtually or online.
    - Website: https://utcaregivers.org
    - Email: utcaregivers@uthealthsa.org
    - Phone: 210-450-8862

- **Alzheimer's Association- San Antonio and South Texas Chapter.** The Alzheimer's Association Provides education and support groups to caregivers and persons living with dementia. You can talk to an expert on any topic related to Alzheimer's Disease or a related dementia using their 24-hour helpline or the online chat option.
    - Website: www.alz.org/sanantonio
    - Chapter Phone: 210-822-6449
    - 24/7 Helpline: 1-800-272-3900

- **WellMed Charitable Foundation Caregiver SOS.** Through the WellMed Charitable Foundation, the Caregiver SOS program offers education, information and support to family members and friends providing care to an older person. Caregiver Specialists are available to provide information and support on how to manage caregiving responsibilities. Teleconnection program that offers one hour learning sessions over the phone.
    - Website: www.caregiversos.org
    - Email: caregiversos@wellmed.net
    - Phone: 866-390-6491

- **Area Agencies on Aging.** Area Agencies on Aging are found throughout the United States. AAAs (said "triple As") can help caregivers access services such as Meals on Wheels, local counseling services, caregiver education and training opportunities, respite care, Medicaid enrollment, support groups, and other community resources. Contact your local Area Agency on Aging office to find out more.

Alamo Area Agency on Aging/ Bexar County Area Agency on Aging
Website: https://aacog.com/
Email: info@askasc.org
Phone: (210) 477-3275

Unable to find your local services?

You can use your zip code to find services using ElderCare Locator either online at https://eldercare.acl.gov/Public/Index.aspx or by calling 1-800-677-1116.

National Caregiving Resources

The following organizations offer a range of high-quality and reliable resources to support family caregivers. Use the search functions within each organization's website to find tools that best meet your needs!

- Family Caregiver Alliance: https://www.caregiver.org

- National Institute on Aging: https://www.nia.nih.gov/health/alzheimers/caregiving

- AARP Prepare to Care Guide (available in multiple languages): https://www.aarp.org/content/dam/aarp/caregiving/pdf/family-caregiving-guide/english.pdf?intcmp=AE-CAR-P2CGD-ENG

- Sage Advocacy & Services for LGBTQ Elders: https://www.sageusa.org/

- Diverse Elder Coalition: https://diverseelders.org/

Veteran's Caregiver Support Services

- Are you or your loved one a veteran? The U.S. Department of Veterans Affairs (VA) provides life-long healthcare services to eligible military veterans, including caregiver supports. Services include evidence-based training programs, respite care, and counseling. Some caregivers may be eligible for a stipend.
    - Website: https://www.caregiver.va.gov/
    - VA Caregiver Support Line: 1-855-260-3274

Resources for Employers

- **Supporting Caregivers in the Workplace: A Practical Guide for Employers:** https://nebgh.org/wp-content/uploads/2017/11/NEBGH-Caregiving_Practical-Guide-FINAL.pdf

- **The Caring Company Harvard Business School Report:** https://www.hbs.edu/managing-the-future-of-work/Documents/The_Caring_Company.pdf

- **Massachusetts Caregiver Coalition Website:** https://macaregivercoalition.org/

- **Family Caregiver Alliance Statistics on Employment and Caregiving:** https://www.caregiver.org/resource/caregiver-statistics-work-and-caregiving/

- **Care Can't Wait Advocacy Coalition Website:** https://www.carecantwait.org/about

Appendix A

C.C. and A. B, Female Caregivers to Mother

We received a call from a family member who was worried that she had been trying to call my mother Saturday night (Saturday before Thanksgiving) and she was not picking up the call. I had just seen my mother the day before, it was Saturday afternoon, and she was in good spirits. We called the house and her friend, who was living with her at the time, answered and stated that my mother went to sleep Saturday at around 5:30/6:00 p.m., stating she was tired and has not woken up since. It is now 10 a.m. on Sunday! Our shock at hearing this was an understatement. We called an ambulance and jumped into our vehicles and drove over to my mother's house immediately. When I arrived, she was unresponsive, there were about a dozen fire fighters working with her, and they told us she had a hypoglycemic episode and is not waking up. She would have to be taken to the hospital immediately. Anger was setting in at this point, as we could not believe the person living with her would not have done anything. My mother was also under chemotherapy treatments, which were extremely aggressive, so her physical appearance made her look so very fragile and unrecognizable as we knew her. This episode had her unconscious for three days. Our hearts sank because we did not know how much this incident would set my mom's health and recovery back. We don't know how much time we have left with her and we knew that this was the beginning of our lives being altered, with now having the responsibility over my mother's health and financial decisions. She was hospitalized and had to go to rehabilitation for a month altogether. It was now my sister and I who needed to take care of our mother.

My sister and I both work full time and have very demanding jobs. She works for the District Attorney's Office and I as an administrator of a non-profit organization. Our only resolve to what we had ahead of us was that we had to do this together and we had to take care of our mother. The journey has been stressful as we balance work and her care. She is now so much better, with receiving the care needed to supervise her medical conditions. My mother has always been a very strong and independent woman. She always said she was ok, and told us not to worry about her. She took care of everyone, not the other way around. She is a survivor and has a lot of faith and optimism about living her life, despite cancer. Over the last eight months, we have had my mother in the hospital, in rehab, moved her into assisted living, set up her financial situations, and cleared out her home and sold her home so she can have security for her current and future care. It has been a lot and even more so, knowing she is still challenged with adjusting physically to challenges because of her episode and continuing to receive chemotherapy for her on-going cancer diagnosis, stage 4. My sister and I continue to work and are appreciative of having compassionate supervisors who allow us to take time off to care for our mother. It is through the support of our employers that we continue to work and provide for our own families/households. My supervisor even gifted me with some of his personal time off hours, as I was about to run out of mine. This supportive environment allows me to feel secure about my job, and asking for time off with the grace of flexibility in the work we do has been invaluable. This support matters the most.

Appendix B

T.D., Female Caregiver to Husband

It is with gratitude that I share the way that my agency has been able to help my husband. You see my husband has slowly gone blind and getting around has been difficult at times. Our agency has a department that assists our Veterans with rides and provided him, at one time, with a 30-day bus pass. In another instance, he needed help when he had to apply for disability, once it was determined he could no longer work because his sight had diminished so badly. The department of aging stepped in and helped him to file for social security disability. As you can imagine, there was a ton of paperwork (that he could not read) that had to be filled out and signed. [Another nice colleague] made time for him to come in to the office and have everything explained to him so he could sign the documents. He went through the process with her and successfully received his benefits some months later from the Social Security Administration. We are currently in the process of asking which one of these departments can help us build a handicap ramp for him to use which will make it safer for him. We are both very grateful for the help he has received and most likely will continue to receive, as the severity of loss of sight has been catastrophic for him and our agency provides so many services that can help him tremendously.

Another wonderful example of flexibility with work is when my mama was diagnosed with Cancer and I was given permission from my supervisor to work remotely from California. I worked from Stanford University Cancer center for 2 months while mama underwent the initial treatment and was finally released to return home. I was able to set up home care services for her and return to Texas comfortable knowing mama was going to receive her care from home. A few years ago, when my husband underwent a cornea transplant, I was also able to flex my hours so that I could be at his side.

In closing, I am very proud of our [workplace] family as we reach out to serve the community of so many diverse needs.

Appendix C

C.Z., Female Caregiver to Sister

My sister and only sibling was diagnosed with cancer on Valentine's Day. No one on either side of our family had ever had cancer except for an uncle who chain-smoked, so we were shocked. She had always been active and healthy, so she was committed to fighting the disease. She made plans for a long, chemotherapy regime and we rallied around her. For once, I was glad about COVID - it had paved the way for me to start working remotely from the town where she lived. But after a few weeks, my sister said that she was lonely much of the day with everyone working. She wondered if I would be willing to just stop working to spend time with her. I didn't hesitate and made arrangements to use my paid time off. I assumed I would then go on Family Medical Leave (FMLA), which is unpaid leave for up to 12 work weeks per year.

The radiation and chemo were much worse than expected, and my sister suffered every possible side effect in the book. The days were a pharmacological puzzle of timing pills and liquids with food, timing without food, sitting up for 2 hours after food, and waking up every 1-3 hours throughout the night to take pain medication. She developed night sweats. Every 2 hours, she would ring her bell for me to help her change clothes and rotate the bed linens. She was often nauseous and weak. By late April, we discovered none of the chemo the oncologists had tried were helping. The cancer was continuing to spread and grow. My sister was now only 80 pounds and failing. She made the difficult decision of stopping all treatment and going on hospice.

We, the general public, are told that hospice is death with dignity – that the person can spend their final days at home surrounded by family and friends who love them. What they don't say is that in many places, especially during COVID where workers shortages have been common and extreme, hospice is actually relying on those family and friends to provide 100% of the care. Hospice said they would provide a physician that we would never see but who would manage the pain medications. The hospice nurse would come out several times a week to check on my sister's health status and order the meds from the invisible doctor. They would provide oxygen, a wheelchair and a hospital bed – equipment that were never needed but were dropped off anyway to sit in the living room. They would not provide any person to assist us, to provide respite or homemaker services, but they would answer the phone 24/7 if we had questions. The one question they couldn't answer was who was going to help us provide hands on care for months.

So, a friend and I started our 24-hour shifts. I would be the caregiver for 24 hours straight from 11 am to 11 am the next day, and then she would take the next 24 hours. I would sleep for a few hours when I got back to my father's house, be awake for a few hours, and then sleep before pulling another all-nighter, etc., etc. etc. We were all exhausted.

My boss at work was always incredibly supportive. When my paid leave was exhausted, she called a meeting with HR to discuss FMLA. They put together the documents and were just about to close the meeting when the HR representative exclaimed, "I forgot. FMLA doesn't cover siblings. It only covers parents, spouse and children." My sister didn't count. What were my options after working for 13 years for the same organization? I learned that I could have 40 hours of "negative" leave. After that, it was considered job abandonment and I would be terminated.

So, I went back to work remotely, caring for my sister and working my 40 hours whenever I could. I am fortunate that I could put together any type of schedule that allowed me to continue to work with pay. Many caregivers don't have that option and can no longer pay their own bills.

I wish I could say that the hospice care improved. But it didn't. The hospice nurse who came out was terrific, but only had a few minutes to stop by each week. When the invisible physician would forget to call in the pain medications before a weekend, it was just lucky that there were two of us – one to stay at the house and one to wake up and run to the pharmacy before they closed. No one from hospice would come out to help when my sister woke up flailing in bed and fell off into the floor. They told us to find a neighbor or relative. At 50 pounds, it still took two of us to get her back on the bed.

They say that growing old is not for sissies. I would say the same for caregiving, particularly working while caregiving. It's so important that we have trained and adequately paid caregivers who work at agencies, and who we can trust to care for our loved ones. It's also important for us as family caregivers to be able to keep our jobs with pay when the family we grew up with – including our siblings, the family we married into, and our family of choice who have no blood relationship ask us to just stop and care for them in their time of need. My sister passed away in late June. And I'm back at work full time.

Appendix D

I.L., Daughter Caring for Mother

"Being a caregiver means you have to really care about your fellow human being when they are down, and you have to find a way to lift them up. I let [my colleagues] know I care and that I pray for all, and if you need to lean on my shoulder, it's always there if you need to cry. I will cry with you if you need hope. I will hope with you if you just need a smile. I listen and smile each and every day with you.

I was given great support when I was taking care of my ill mother before she passed away and that was very helpful to me to know that I could talk to someone about my feelings."

I.L.'s mother, below.

L.O., Daughter Caring for Mother

"Working with individuals willing to be supportive and understanding has made a difference in my caregiving journey. [Colleagues and supervisors ensured I could care for my loved one] by taking the time to sit down and listen. They also directed me to resources and someone in our agency who has knowledge, as well as access to various programs. [I would want employers to know that caregivers in the workplace] will [have] days when they feel drained, and also depressed at times from the lifestyle changes that occurred during the caregiving process, [and this should be accepted]. "

L.O., with her mother below.

S.J.P., Female Caregiver to Loved One

"[My caregiving journey] helped me grow as a humbler person, [and it] gave me confidence and a sense of purpose in life. [It made] me think that I can do good for others and share what I have with others. [Colleagues and supervisors supported me] by letting me be with my loved one at the time needed, and [by] providing support. [They] always kept in mind that self-care is needed to continue providing good service [to our clients]."

Appendix E

Additional Caregiver Testimonies

E.M.G., Female Caregiver to Mother

"I made sure to earn and maintain PTO to use when needed for doctor appointments, since my previous workplace didn't have options. [However, colleagues and supervisors ensured I could care for my loved one by] giving me the time to take care of my mom after my dad died. [I would want employers to know] that they should be honest up front if they do not want a caregiver in their workplace, to avoid making promises they cannot keep."

M.V., Female Caregiver to Loved One

"[What really made a difference in my workplace was] my supervisor understanding my situation, and being open minded. Colleagues would encourage me, and my supervisor was there to listen at times, and understand my situation, or ask about my situation. [I would like an employer to know that] presently [the caregiving] is overwhelming, and it is a 24/7 duty. My job is always my priority, however, and I will always give my all even in my situation."

Quotes have been modified for readability

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