

Some background on family caregivers in the United States today

Most jobs don't require employees to be available 24 hours a day, 7 days a week. Yet, for many family caregivers, that is exactly what's expected of them. They face challenges day and night. Caring for a spouse with multiple sclerosis (MS) or a child with special needs can be non-stop. On top of that, caregivers sometimes suddenly need to rush to the hospital or leave work at the drop of a hat.

According to 2015 estimates, there are approximately 43.5 million unpaid caregivers in the US.¹ What's more, six out of 10 family caregivers work full- or part-time in addition to juggling their caregiving responsibilities at home.² For most caregivers, days just aren't long enough!

This caregiving crisis directly affects the workplace, with employees who serve as care partners reporting missing work due to caregiving responsibilities.¹ Caregivers also suffer long-term economic effects from their responsibilities, including suffering economic losses, increased rates of absenteeism, and decreases in their ability to advance at work.³ For example, over half of caregivers for loved ones with MS reported missing an average of at least 7.3 days of work over a one-year period due to their caregiving responsibilities.⁴

These caregiving responsibilities affect workplace performance, according to both employer and employee. Eighty percent of employees who have these additional responsibilities admitted that their role as care partners affected their productivity at work, and nearly a quarter of companies feel that caregiving responsibilities affected their employees' performance.⁵ While the impact of the responsibility of being a care partner on the workplace is clear, it is not being addressed by employers. More than half of employers (52%) do not collect data on the caregiving responsibilities of their employees.⁵

Note to Employers

More than 22 million Americans, or 15% of the workforce, provide care to a loved one.⁶ The cost of caregiving is also shouldered by employers, with total cost of lost productivity being estimated at over \$30 billion.⁷ These costs are primarily due to replacing employees after they leave the workforce (\$6.6 billion), workday interruptions (\$6.3 billion) and absenteeism (\$5.1 billion).⁷ Employer-paid healthcare costs are impacted as well, with caregiving employees costing eight percent more than employees overall.⁸ Caregivers' careers and livelihoods are impacted by providing care. More than half of caregivers felt their career was negatively impacted by their caregiving situation.⁹ Caregivers reported loss of income and even loss of employment due to providing care.⁹

If not asked directly, employees are reticent to divulge their additional caregiving responsibilities, often worrying that they will be perceived as less committed to their jobs and that they may not progress as quickly in their careers as colleagues in different situations. Employers have much to gain by implementing caregiver-friendly workplace policies, and the survey questions below will help highlight areas where you are providing optimal employee support around care partnering as well as the area(s) where improvements can be made.

The manner in which a survey such as this is disseminated to employees who see themselves as care partners using the definition below, or some comparable definition, is entirely up to your discretion.



Survey Introduction

In this survey, we are interested in learning more about the care you provide to a family member or friend who has a chronic, long-term health condition. A "care partner" is commonly defined as an individual whose intent is to help the patient in their disease management, who may provide assistance with personal care and routine needs. The valuable care you provide can help this person maintain an independent lifestyle and can include tasks like medical assistance, cooking, cleaning, shopping, giving medications, toileting assistance, and other tasks. Please be assured that your answers will remain anonymous.

The input you provide in this survey will directly inform decision-making so that we can provide better support to our employees who are serving as caregivers.

Care Responsibilities

1. During the past year, did you have to take time away from work (either paid or unpaid) to care for a chronically ill family member or friend?

- a. Yes
- b. No

2. How long have you been providing care for this family member or friend?

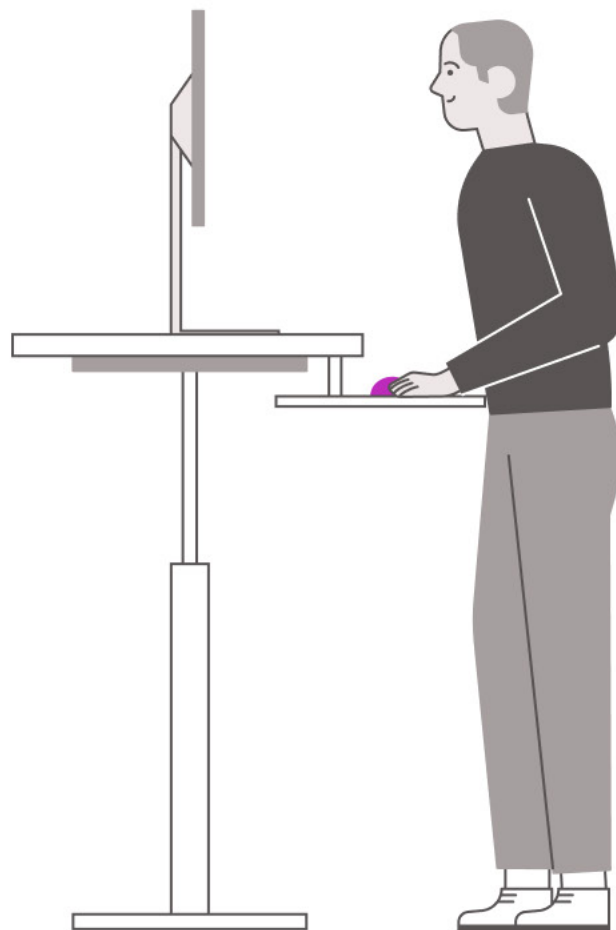
- a. Less than one year
- b. 1 to 3 years
- c. 4 to 10 years
- d. More than 10 years

3. What is your relationship to the person for whom you provide care?

- a. Spouse or partner
- b. Adult child
- c. Child
- d. Parent
- e. Grandparent
- f. Sibling
- g. Friend or neighbor
- h. Other _____

4. What is your care recipient's primary illness, disability, or condition that makes you the family caregiver? Select the best response below.

- a. Accident or trauma resulting in spinal cord or traumatic brain injuries
- b. ALS/Lou Gehrig's disease
- c. Alzheimer's disease
- d. Arthritis
- e. Autism
- f. Blindness, macular degeneration, vision loss
- g. Cancer
- h. Cerebral Palsy
- i. Deafness, hearing loss
- j. Mental health issues (addiction, depression, bi-polar, schizophrenia)
- k. Diabetes
- l. Epilepsy (seizures)
- m. Fibromyalgia
- n. Heart disease, stroke or related disorders
- o. HIV/AIDS
- p. Huntington's disease
- q. Hypertension/high blood pressure
- r. Lung/pulmonary disease (COPD, Emphysema, Asthma)
- s. Lupus
- t. Down's syndrome
- u. Intellectual/developmental disability
- v. Multiple Sclerosis
- w. Parkinson's disease
- x. Sickle cell
- y. Spinal disease or disorder
- z. Other



5. How old is your care recipient?

- a. Under 18
- b. 18-24
- c. 25-34
- d. 35-44
- e. 45-54
- f. 55-64
- g. 65-74
- h. 75 or older

6. With which of the following do you assist your care recipient? (Select as many as apply)

- a. Bathing or showering
- b. Toileting
- c. Incontinence
- d. Getting dressed
- e. Feeding
- f. Transferring (Getting in and out of beds, chairs, the car)
- g. Housework
- h. Managing finances (bills, insurance paperwork, etc.)
- i. Managing medications (ordering prescriptions refills, going to pharmacy, etc.)
- j. Giving your care recipient medications
- k. Transportation (driving to and from appointments, arranging travel)
- l. Grocery shopping
- m. Preparing meals
- n. Arranging or supervising paid services (Home help or home health, cleaning, nurse/aides)
- o. Other (Please describe) _____

7. How much time do you spend each week providing these services?

- a. Less than 5 hours per week
- b. 6 to 20 hours per week
- c. 20 to 40 hours per week
- d. More than 40 hours per week

Impact on Quality of Life

8. How would you describe your level of stress in relation to your role as care partner?

- a. I feel stress every day.
- b. I feel stress every now and then.
- c. I don't feel stress related to my caregiving responsibilities.
- d. I am not sure.

9. Do your caregiving responsibilities affect your health?

- a. I feel that my health frequently suffers as a result of my caregiving responsibilities.
- b. I feel that my health sometimes suffers as a result of my caregiving responsibilities.
- c. I don't feel that my health suffers as a result of my caregiving responsibilities.
- d. I am not sure.

10. Please indicate how frequent each statement has been true for you in the **past month**.

	Always	Frequently	Sometimes	Seldom	Never
My level of stress and worry has increased.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get support from family and friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried about our insurance coverage.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like I know enough about my loved one's illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel overextended with all that I have to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Impact on Employment

Just a reminder that all your answers will remain anonymous.

11. How familiar are you with the Family Medical Leave Act (FMLA) and the provisions it includes relating to the role of care partners?

- a. Very familiar
- b. Familiar
- c. Not familiar
- d. Not at all familiar

12. Please indicate how often you encounter these issues.

	Always	Frequently	Sometimes	Seldom	Never
There are times when my caregiving responsibilities affect my work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find it hard to balance my caregiving and my other responsibilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My role as care partner has prevented me from moving ahead at work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My caregiving responsibilities affect my productivity at work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think I am seen as less committed to my job than other people who don't have caregiving responsibilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13. Are there other ways that being a care partner affects your ability to do your job?

14. Please indicate to what extent you agree with each statement.

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
I feel that the HR department at my workplace has shown that they want to support my role as care partner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is important to me that my employer is asking me about my role as care partner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would be more likely to stay in a job where my needs as a caregiver were met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My employer has demonstrated flexibility that has helped to accommodate my role as caregiver.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



15. Please indicate to what extent you agree with each statement.

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
My role as care partner may affect my ability to keep my job.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel comfortable talking to my employer about my caregiving responsibilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel my existing benefits are adequate to cover my needs as a caregiver.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are additional accommodations that my job could make to support me as a care partner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would describe my company as a caring company.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Workplace Accommodations (OPTIONAL)

16. How helpful would it be if your employer made accommodations to assist in your caregiving responsibilities?

	Very Helpful	Helpful	Not Sure	Not Helpful	Not at all Helpful
Information about taking time off to care for your loved one.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
'Lunch and Learn' sessions with experts in the management of chronic illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
On-site care partner support groups.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Easy access to behavior health benefits.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Flexible work schedule.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telecommute options, where appropriate.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. Do you have any additional suggestions for specific ways that your workplace could assist you in your role as care partner?

Demographic Information

18. What is your gender identity?

- a. Female
- b. Male
- c. Gender nonbinary
- d. Other
- e. Prefer not to say

19. What is your race or ethnicity? (Select all that apply)

- a. America Indian or Alaskan Native
- b. Asian
- c. Black or African American
- d. Native Hawaiian or Other Pacific Islander
- e. White
- f. Hispanic, Latino or Spanish
- g. Other
- h. Prefer not to answer

20. Marital status

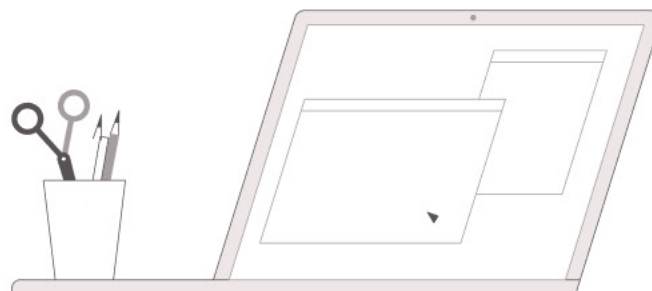
- a. Single, never married
- b. Married or in a domestic partnership
- c. Previously married

21. Age

- a. Under 18
- b. 18-24
- c. 25-34
- d. 35-44
- e. 45-54
- f. 55-64
- g. 65-74
- h. 75 or older

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