



Working Caregiver Survey Instrument

Thank you for your interest in taking this survey! The purpose of this survey is to help your employer better understand how family caregiving responsibilities impact their employees.

Things you should know about this survey:

- Your answers to the questions are anonymous.
- Results will be shared with your employer.
- We may also use survey responses to better understand the needs of employed caregivers more generally. Any reports will be summaries and no individual's answers can be identified.
- You can choose whether or not to take this survey and can skip questions or end the survey at any time.

If you are willing to participate in the survey, please answer the questions below. This survey will take less than 10 minutes to complete.

Think about the past 6 months. In that time, have you helped a family member or friend who has a chronic illness, disability, or other limitation due to age or poor health?

Check all that apply.

- Driving to doctor appointments or other services
- Arranging or preparing meals
- Grocery shopping
- Assisting with home maintenance, repairs or yard work
- Providing personal care (e.g., bathing, dressing, feeding)
- Completing forms or documents (e.g., legal, insurance)
- Looking for or applying for support services or resources (e.g., respite care)
- Assisting with money management (e.g., paying bills)
- Housekeeping tasks (e.g., cleaning, laundry)
- Assisting with medications (e.g., setup, dosing)
- Assisting with other nursing or medical tasks
- Arranging services for a long distance friend or relative
- Providing financial support (e.g., giving money for household expenses)
- Other care due to illness, disability, aging, or health limitations
- No, I have not cared for a family member or friend with a health limitation

Think about the past 6 months. In that time, have you cared for a child or young adult (17 or younger) who has a chronic illness, disability, or other special healthcare need? Please consider care beyond what is typical for other similarly aged children. Check all that apply.

- Driving to doctor appointments or other services, other than regular check-ups or routine care
- Providing personal care (bathing, dressing, feeding), beyond what other similar-aged children need
- Completing forms or documents (legal, insurance, social security, individual education plans) related to their special healthcare need
- Looking for or applying for support services or resources (e.g., respite care)
- Coordinating activities and educational services that meet the child's needs (related to their illness, disability, or health limitations)
- Scheduling appointments or coordinating medical care across healthcare providers beyond what other similar-aged children need
- Assisting with medications (setup, dosing) related to their special healthcare need
- Assisting with other nursing or medical tasks related to their special healthcare need
- Other care due to illness, disability, or health limitations
- Assisting with home maintenance, repairs or yard work
- No, I have not cared for a child or young adult with a health limitation

The following questions only appear for those who have answered either of the above questions with a caregiving task.

For how many individuals do you currently provide care?

- One
- Two
- Three
- Four
- Five or more

Who are you providing care for? Check all that apply.

- Parent or parent-in-law
- Sibling
- Spouse/Significant other/Partner
- Child
- Grandparent
- Other relative
- Friend
- Neighbor

Which conditions does this person/do these people have? Check all that apply.

- Dementia, Alzheimer's or other memory problem
- Emotional or mental health problem
- Intellectual or developmental disability
- Long-term health condition (chronic conditions such as diabetes, COPD [chronic obstructive pulmonary disease], chronic pain)
- Other health condition (such as heart attack, broken bone, recovery from surgery)
- Other care needs (such as aging, being frail, mobility issues)

If you care for more than one person, please think of the person for whom you provide the most care when responding to the following questions.

Are you the primary caregiver for the individual?

- Yes
- No

Who does this person live with?

- No one - they live alone
- With you
- With another family member
- With an unrelated person, such as a friend or roommate
- No
- Other

How far from you does this person live?

- Less than an hour away
- One hour or more away

Does this person live in a residential care or assisted living facility?

- Yes
- No

How long have you been providing care for this person?

- Less than one year
- 1 - 5 years
- 6 - 10 years
- 11 - 15 years
- 16 years or more

In a typical week, about how many hours of care do you provide for this person?

- 0 - 7 hours per week
- 8 - 14 hours per week
- 15 - 21 hours per week
- 22 hours or more per week

Thinking now of all the care you provide to the family members or friends you listed above, how many hours of care do you provide overall in a typical week?

- 0 - 7 hours per week
- 8 - 14 hours per week
- 15 - 21 hours per week
- 22 hours or more per week

Do you think you will be able to continue providing care as long as it is necessary?

- Yes, with the same help I currently receive
- Yes, but with additional help
- No
- Unsure

When was the last time you were able to take a vacation that allowed you time away from your caregiving responsibilities?

- Less than 6 months ago
- Between 6 - 12 months ago
- Between 13 months - 2 years ago
- More than 2 years ago

Are you using respite resources to allow for breaks from caregiving?

- Yes, friends/family members help me to take a break from caregiving
- Yes, I use respite services paid with respite funding
- Yes, I use self-pay respite services
- No, I do not qualify for respite funding
- No, I am not familiar with respite
- No, I am not interested in respite

In the past year, have your caregiving responsibilities caused you to do any of the following?

Check all that apply.

- Arrive at work late
- Leave work early
- Miss days of work
- Take leave of absence
- Be at work but feel unable to focus
- Use break or lunch times to arrange for caregiving services
- Respond to calls or emergencies during work hours
- Rearrange your work schedule
- Cut hours of work
- Turn down work-related travel
- Turn down a promotion
- Turn down work relocation
- Consider changing employers
- Consider leaving work entirely
- Other work impact
- My work was not impacted by my caregiving role

If you missed work due to caregiving, which of the following have you used to fulfill caregiving responsibilities? Check all that apply.

- Sick leave
- Flexible hours
- Vacation
- Personal time or other paid time off
- Work from home
- Time off without pay
- I have not needed to miss work due to caregiving

Did you use FMLA (Family Medical Leave Act) protections during your leave?

- Yes
- No
- Unsure/Prefer not to answer

Overall, has providing or arranging care for the individual you are caring for made your current employment more difficult?

- Yes
- No

If you answered YES above, please provide an example below. Since results will be shared with your employer, please note that information you provide may make it possible to identify you.

Please answer this question even if you are not currently a caregiver. This will indicate what is of greatest interest, should you be in a caregiving role in the future. Please check all of the following family caregiving topics about which you would like to learn more. Check all that apply.

- Communicating with family members
- Communicating with health care professionals
- Communicating with your supervisor and work colleagues about your family caregiving situation
- Caregiving benefits offered through your employer
- Community resources to assist with caregiving tasks and responsibilities (e.g., in-home assistance, educational classes, support groups)
- Legal, financial and/or health care planning (e.g., powers of attorney for health care and finances, guardianship, estate planning)
- Finding and hiring paid help
- Exploring residential long-term care options (nursing home, assisted living facilities and other housing options)
- Juggling work and caregiving
- Coping with caregiving responsibilities, including stress management
- Personal care skills such as bathing, transferring, and feeding
- Dealing with challenging behaviors (wandering, asking same question, etc.)
- Strategies to approach difficult decisions (e.g., taking away driver's license, needing paid help, moving to care facility)
- Dealing with loss and grief
- Understanding how your relationships change throughout the caregiver journey
- Long term care insurance
- Information on how to balance work and caregiving responsibilities
- Information on how to balance family life and caregiving responsibilities
- None

The following questions only appear for all respondents to the survey, even if they did not provide a caregiving task in the past six months.

How would you prefer to receive caregiving information if it were made available at your workplace? Check all that apply.

- Lunchtime seminars
- Before or after work seminars
- Employee newsletters
- Fact sheets
- Individual meetings with someone to help you problem solve
- On-site support groups
- Printed directory of caregiver services
- E-mail
- Online
- Other, please specify:

Gender

- Male
- Female
- Nonbinary
- Prefer not to answer
- Another option not listed here

Age

- 25 and under
- 26 – 35
- 36 – 45
- 46 – 55
- 56 – 65
- 76 and older
- Prefer not to answer

Race/Ethnicity

- American Indian or Alaska Native
- Asian
- Black or African-American
- Hispanic/Latinx/Spanish origin
- Middle Eastern or Northern African
- Native Hawaiian or other Pacific Islander
- White or Caucasian
- Prefer not to answer
- Another option not listed here (please specify)

Number of years employed by organization

- Less than one year
- 1 - 5 years
- 6 - 10 years
- 11 - 15 years
- 16 - 20 years
- 21 - 25 years
- 26 - 30 years
- 31 years or more
- Prefer not to answer

Thank you for completing the Employed Caregiver Survey.