



The U.S. Carer Well-Being Index

The Pandemic Makes a Difficult Job Even Harder for Family Caregivers



The stresses on caregivers have long existed, but in 2020, the uncertainty of the pandemic made them even greater. The pandemic significantly affected healthcare systems and caused substantial disruption for family caregivers (more inclusively referred to as unpaid caregivers), in ways that put their economic, physical, and psychological well-being at risk. In producing the Carer Well-Being Index, Embracing Carers® aims to detail the ways in which the pandemic disproportionately harms caregivers in the U.S. and around the world—and to identify key societal solutions and specific actions that can address their needs during the pandemic and beyond.

The Carer Well-Being Index

The Carer Well-Being Index is a global research study commissioned by Embracing Carers® and fielded in partnership with an independent, third party market research provider and nongovernmental organizations across 12 countries, including the United States. Respondents included 750 unpaid caregivers (or “carers”) in each country that care for someone with a long-term illness, physical disability, or cognitive/mental condition.

Rising Demands

During these unprecedented times, the pandemic placed added pressure on caregivers. More than ever before, they are shouldering heavy burdens.

- **New Carers:** When the pandemic hit, some—particularly younger generations and parents—had to step into a caregiver role for the first time. About 13% became caregivers for the first time.
- **Time Increase:** Demands on caregivers’ time increased because of the pandemic. Before COVID-19, carers spent an average of 20.6 hours per week on caregiving. During the height of the pandemic, carers spent 28.1 hours/week, an increase of nearly 40%. And about 30% are expecting their caregiving to increase to 41+ hours a week even after the pandemic.
- **Emotional Support:** 77% said providing emotional support was their primary responsibility as caregivers, even as they needed support of their own.
- **Increased Dependence:** 45% of caregivers said the person(s) they care for is/are relying on them more than ever before.



Changed Responsibilities

While caregivers have long faced hurdles, the pandemic has exacerbated specific tasks and responsibilities.

- **Managing Technology:** As the pandemic moved us to a virtual world, 67% of caregivers said managing technology for virtual medical appointments and connecting with loved ones had increased during the pandemic. And 53% said they needed additional training on how to use/access telehealth and other online tools.
- **Emotional Support:** Caregivers are also providing significantly more emotional support for their loved ones and their own needs are taking a back seat. 91% said they have put the needs of the person(s) they are caring for above their own during the pandemic.
- **Respite Needed:** 33% of caregivers say the biggest challenge they have faced during the pandemic is the inability to take a break.



The Toll on Caregivers

Being a caregiver comes at a cost, often on the caregivers' well-being, which includes physical, mental, financial, and social outcomes



- **Emotional/mental health: 68%** of caregivers say the pandemic has worsened their emotional health.
- **Financial: 54%** of caregivers say the pandemic has worsened their financial health, with more of their money going for food, household bills and medical equipment.
- **Social: 50%** say being a caregiver negatively impacts their relationship with friends. And while most acknowledge the value of connecting with other caregivers, only 15% talk with other caregivers regularly to support mental health.
- **Physical: 44%** say the pandemic has worsened their physical health, citing lack of sleep and exercise, poor diet, and postponing their own medical appointments.



Inequities in Caregiving

Women and racial/ethnic minorities are facing harsher experiences and inequities as caregivers.

- **Financial Inequity:** Women caregivers have fewer financial resources and receive less support. Women caregivers are more likely to be in the low-income tier (HHI of below \$50K/year) than men caregivers (56% vs. 36%, respectively).
- **Workplace Policies:** Ninety-five percent of women agree that employers should provide additional flexibility policies and support for caregivers/carers.
- **Demands on Time:** Even before the pandemic, women were more likely to be spending at least 30 hours a week on caregiving responsibilities, and that time commitment has only increased during the pandemic. 42% of women say they continue to spend 30+ hours/week on caregiving compared to 31% of men.
- **Job Insecurity:** Of those whose financial health has worsened during the pandemic, racial/ethnic minority caregivers (28%) are more likely than white caregivers (14%) to have had their salaries reduced.



Improving Support for Unpaid Caregivers

Across public and private sectors, everyone must play a role in supporting caregivers – it is a societal responsibility to care for caregivers.

Financial support

- Create a national mandate for paid family and medical leave for unpaid caregivers
- Work on bipartisan, legislative solutions like amending federal tax policy to provide greater (and uniform) support for unpaid caregivers, potentially including tax credits, enhanced deductibility for the direct costs of caregiving, etc.
- Incentivize employers to develop support programs for employees who are unpaid caregivers- giving them flexible working hours, paid family medical leave, etc.

Emotional/mental well being

- Provide respite care services that are flexible and easy to secure.
- Create and promote points of social connection with peer caregivers.
- Provide and promote advice/therapy hotlines for real time emotional support.
- Offer and promote quality mental health aid, with top-tier providers, that is easy to navigate, easy to access and at no cost.

Inequities in Caregiving

- Promote and implement policies that provide financial, social, and emotional support for women caregivers, especially those in the low-income tier (HHI of below \$50K/year).
- Create subsidized internet/broadband connections in underserved communities to ensure access to telehealth and ongoing care.
- Develop research and increase awareness of the persistent inequities facing racial/ethnic minority caregivers.



More information

About Embracing Carers® – Embracing Carers® is a global initiative led by Merck KGaA, Darmstadt, Germany, operating as EMD Serono, MilliporeSigma and EMD Electronics in the United States and Canada. It is a collaboration with leading caregiver organizations around the world designed to increase awareness, discussion, and action about the often-overlooked needs of caregivers. The Caregiver Action Network and the National Alliance for Caregiving are the leading U.S. Embracing Carers® advisors. For more information visit; www.embracingcarers.com

Index Study Methodology - The study was fielded September 3-24, 2020 via an online survey in the United States. Outgoing sample collected was balanced to U.S. Census to allow qualifying respondents to fall out naturally. Light weighting was applied on race/ethnicity to achieve better national representation. At the 95% confidence level, the full United States unpaid caregiver sample has an estimated margin of error of +/- 3.6 percentage points.