The U.S. Carer Well-Being Index

Who Cares for Caregivers?
Perspectives on COVID-19
Pressures and Lack of Support
While it is necessary to take care of your loved one or friend, it is also very important for you to take care of yourself. If we as caregivers do not find time to do something that we enjoy doing outside of the caregiving role, you will not be any good for the person when they need us most.

—60-year-old Female caring for someone with Parkinson’s Disease

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Setting the Stage

**Embracing Carers** is a collaboration through which leading caregiver organizations around the world work to increase awareness, discussion and action about the often-overlooked needs of people who provide unpaid care for others. According to AARP and National Alliance for Caregiving (NAC), more than 47.9 million people*, provide care for a chronically ill, disabled, or aged family member or friend during any given year.

In order to illuminate the challenges caregivers face, Embracing Carers conducted a Global State of Care survey in 2018 to determine the unmet needs of caregivers and the impact that caring for others has on their own health and well-being. Based on what the survey found, Embracing Carers has implemented **five global priorities** that serve as a foundation for the development of legislation, policy and programs to support unpaid caregivers around the world.

Many of the stresses on caregivers have long existed, but in 2020, the uncertainty of the pandemic has made them even greater. It has significantly affected healthcare systems and has caused substantial disruption for unpaid caregivers, in ways that put their economic, physical and psychological well-being at risk.

In producing the 2020 Carer Well-Being Index, Embracing Carers aims to detail the ways in which the pandemic disproportionally harms caregivers around the world—and to identify key societal solutions and specific actions that can address their needs during the pandemic and beyond.

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**Heather Connor,**
*Head of Global Communications, Healthcare at Merck KGaA, Darmstadt, Germany*

**Lynn Taylor,**
*Head of Global Healthcare Government & Public Affairs, Merck KGaA, Darmstadt, Germany*
Research approach and methodology

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 non-governmental organizations across 12 countries. 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. The conditions they care for include cancer, Multiple Sclerosis, Parkinson’s Disease, Dementia, Alzheimer’s, Spinal cord injury, Muscular Dystrophy, cognitive/mental condition or Congestive Heart Failure.

The content in this report highlights key learnings specific to caregivers within the United States*.

*For further details on the methodology and demographic profile of American caregiver respondents, please visit the Appendix.
Five key themes emerged from the 2020 Carer Well-Being Index

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

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

III. The Toll on Caregivers
Though there are rewarding elements to being a caregiver, it does still come at a cost – and it’s often on the caregivers’ well-being, which includes physical, mental, financial and social outcomes.

IV. Inequities in Caregiving
Women and racial/ethnic minorities are facing harsher experiences and inequities as caregivers.

V. Path to Solutions
Across public and private sectors, everyone must play a role in supporting caregivers – it is a societal responsibility.
I: Rising Demands

“I think taking care of them, the house, my 4 kids, as well not having time for myself and not being able to go anywhere has just made things stressful.”

– 40-year-old Female caring for two individuals with ongoing/long-term cognitive/mental conditions
When the pandemic hit, some—particularly younger generations and parents—had to step into a caregiver role for the first time.

**Duration as a Caregiver**

- 76% of those surveyed have been a caregiver for 5 years or less.

**First-Time Caregivers as a result of COVID-19**

- 13% became a caregiver for the first time as a result of the pandemic.
  - 18% Parents
  - 18% Gen Z & Millennials

Q4. How long have you been a caregiver/carer? Base: US Caregivers n=750
Q7. Did you become a caregiver/carer for the first time as a result of the Coronavirus/COVID-19 pandemic? Base: US Caregivers n=750; Gen Z and Millennial Caregivers n=348.
Demand on caregiver’s time increased because of the pandemic—this commitment is predicted to continue in the future.

Average Hours Caregivers Spend on Caregiving (per week)

<table>
<thead>
<tr>
<th>Timeframe</th>
<th>Average Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before coronavirus hit/entered</td>
<td>20.6</td>
</tr>
<tr>
<td>country</td>
<td></td>
</tr>
<tr>
<td>During the height/peak of</td>
<td>28.1</td>
</tr>
<tr>
<td>coronavirus in the country</td>
<td></td>
</tr>
<tr>
<td>Now</td>
<td>28</td>
</tr>
</tbody>
</table>

This is even higher among employed caregivers as they are spending an average of 26.6 hours per week providing care now—a **increase of 8.8 hours** since before the pandemic.

30% of caregivers believe they will be spending, on average, **41+ hours** a week on caregiving in the future due to the impact of the coronavirus.
Amid trying and uncertain times, three in four caregivers provide emotional support.

Top Responsibilities as a Caregiver:

- Providing emotional support: 77%
- Preparing meals: 70%
- Transportation: 68%
- Home maintenance: 67%
- Managing doctor appointments: 67%
- Giving/Managing medications: 59%
- Helping with personal hygiene: 51%
- Managing their finances: 50%

Even higher among female caregivers (80%) compared to male caregivers (70%).

In addition to helping mitigate emotions, most caregivers own the responsibilities of preparing meals, providing transportation, maintaining the home and doctor’s appointments for the one(s) they love.

Q6. What are your primary responsibilities as a caregiver/carer? Select all that apply. Base: US Caregivers n=750; Base: Female Caregivers n=499; Base: Male Caregivers n=250

Embracing Carers is supported by EMD Serono
A complicated dynamic: caregivers are navigating mixed emotions as they experience rising pressures

- 45% say the person(s) they care for is/are relying on them more than ever before
- 88% agree that caring for someone during the Coronavirus is hard but it is also very rewarding
- 44% say the person(s) they care for is/are appreciative of their efforts
For many, the pandemic has made caregiving significantly harder as they juggle more work and more roles.

65% say the pandemic has made caregiving harder.

“IT IS HARDER FOR ME TO GET THE THINGS SHE NEEDS. I am afraid to go to store for groceries and medications. I do not ask for help at all because I am afraid for others to come into our home for safety reasons. I try so hard to keep her safe.”

– 67-year-old Female taking care of someone with Cancer, a diminishing physical disability and chronic life-limiting illness.

“I am having to spend more time explaining things and procedures to the person as they are mentally and physically handicapped and do not fully understand what is going on to make drastic life changes.”

– 73-year-old Male taking care of someone with ongoing/long-term cognitive/mental condition and an artificial heart valve.

“I spend more hours per week with the individual in isolation and perform more cleaning tasks. Since we are both high risk individuals, the added stresses of shopping and working during the pandemic lead to mental health instability.”

– 66-year-old Female taking care of someone with an ongoing/long-term cognitive/mental condition.
“Caregiving has become a lot harder. So many things have changed in this world, like there are certain stores that aren't open, certain places that aren't safe to bring someone who is immune system compromised and everyone's mental health has gotten worse. I have to be a shoulder to cry on, but I don't really have my own shoulder to cry on.”

– 22-year-old Female caring for two individuals with an ongoing/long-term cognitive/mental condition and gastrointestinal disorder

II: Changed Responsibilities
Three Pressure Points: Technology, Emotional Support and Housework

Responsibilities That Have Increased Due to the Pandemic:

- Technology
- Emotional Support
- Housework

Q10. How have each of your responsibilities changed as a result of the Coronavirus/COVID-19 pandemic? - Increased Summary Base: US Caregivers n=750
As the country moved from a physical world to virtual settings, caregivers’ telehealth and technology usage increased, fueling a desire for specific technology trainings.

### Top Responsibilities That Have Increased Due to the Pandemic:

<table>
<thead>
<tr>
<th>Responsibility</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing the technology needed for telemedicine/telehealth/virtual medical appointments</td>
<td>64%</td>
</tr>
<tr>
<td>Providing emotional support</td>
<td>57%</td>
</tr>
<tr>
<td>Managing the technology needed for the person(s) to keep in touch with loved ones</td>
<td>48%</td>
</tr>
<tr>
<td>Home maintenance and housekeeping</td>
<td>43%</td>
</tr>
<tr>
<td>Preparing meals</td>
<td>40%</td>
</tr>
<tr>
<td>Advocating for the person’s care</td>
<td>39%</td>
</tr>
</tbody>
</table>

**NET: Managing technology***

- 67%

53% of caregivers need additional guidance/training on how to use telehealth/online tools/mobile apps for caregiving.

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*Managing technology NET consists of the total respondents who chose ‘managing the technology needed for telemedicine/telehealth/virtual medical appointments’ and/or ‘managing the technology needed for the person(s) to keep in touch with loved ones’ as top responsibilities that have increased due to the pandemic.

Q10. How have each of your responsibilities changed as a result of the Coronavirus/COVID-19 pandemic? - Increased Summary Base: US Caregivers n=750
Q16. To what extent, if at all, do you agree with each of the following statements? - Agree Summary Base: US Caregivers n=750
Caregivers are also providing significantly more emotional support for their loved ones and their own needs are taking a back seat.

**Top Responsibilities That Have Increased Due to the Pandemic:**

<table>
<thead>
<tr>
<th>Task</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
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</table>

91% say they’ve put the needs of the person(s) they are caring for above their own during the pandemic.

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Q10. How have each of your responsibilities changed as a result of the Coronavirus/COVID-19 pandemic? - Increased Summary Base: US Caregivers n=750
Q11. In a few words/sentences, please explain why being a caregiver/carer is more difficult as a result of the Coronavirus/COVID-19 pandemic. Base: US Caregivers n=703
Q24. To what extent, if at all, do you agree with each of the following statements? - Agree Summary Base: US Caregivers n=750

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“I feel overwhelmed having to be there for my family and my father all at the same time.”

– 43-year-old Male taking care of someone with Alzheimer’s, Dementia
As the world quarantined, caregivers’ responsibilities at home grew—leaving little time for caregivers to take a break.

**Top Responsibilities That Have Increased Due to the Pandemic:**

- Managing the technology needed for telemedicine/telehealth/virtual medical appointments: 64%
- Providing emotional support: 57%
- Managing the technology needed for the person(s) to keep in touch with loved ones: 48%
- Home maintenance and housekeeping: 43%
- Preparing meals: 40%
- Advocating for the person’s care: 39%

30% say the biggest challenge they’ve faced as a caregiver during the pandemic is the inability to take a break.

55% say the biggest challenge they’ve faced as a caregiver during the pandemic is the inability to take a break.

"My house is crowded and stressful all the time now. I’m cleaning up and cooking more than usual.

– 39-year-old Male taking care of someone with CNS Lymphoma"
“I miss seeing our family and having friends come over to see us. Most of our friends are our age and they are doing what is necessary to keep from getting the virus.”

– 83-year-old Female caring for someone with a spinal cord injury and a broken neck
Most caregivers are experiencing unprecedented levels of burnout

Since the Beginning of the Pandemic:

- 79% have had to sacrifice more of their personal life for the individual(s) they care for
- 72% say caring for someone during the pandemic has caused them to feel more burnt out than ever before

Q24: To what extent, if at all, do you agree with each of the following statements: Agree Summary Base: US Caregivers n=750; Gen Z and Millennial Caregivers n= 348
The pandemic has impacted key aspects of caregivers’ well-being

1. Emotional/Mental Well-Being
2. Financial Well-Being
3. Social Well-Being
4. Physical Well-Being

Q5. How, if at all, does being a caregiver/carer impact each of the following aspect of your life currently? Base: US Caregivers n=750; *Base: Employed US Caregivers n: 415; **Base: Spouse/Partner n=433

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Feeling isolated, unsupported and inadequate are contributing to caregiver’s worsening emotional and mental state.

Top Reasons Why Caregivers’ Emotional/Mental Health Has Worsened Due to the Pandemic
(among caregivers whose emotional/mental health worsened)

- 39% Physical distancing/sequestering orders have made me feel isolated and alone
- 36% I am worried about having enough money to pay for everything the person/people I am caring for need
- 35% I have even less time to spend with my family and friends
- 32% I don't feel like I have anyone to turn to for support
- 31% I feel like nothing I ever do as a caregiver is enough
- 30% I am more afraid than ever before that the person/people I care for is/are going to die

68% of caregivers say the pandemic has worsened their emotional/mental health.

Q12. In general, do you feel Coronavirus/COVID-19 has improved or worsened each of the following aspects of your health/wellbeing? Base: US Caregivers n=750
Q17. From the list below, which, if any, of the following statements describe why your emotional/mental health has worsened due the Coronavirus/COVID-19? Base: US Caregivers n=508
Many caregivers are adversely impacted by COVID-19’s effect on their financial well-being

54% of caregivers say the pandemic has worsened their financial health

Q12. In general, do you feel the Coronavirus/COVID-19 has improved or worsened each of the following aspects of your health/wellbeing? Base: US Caregivers n=750
Q20. Now, please select from the below list, which, if any, of the following statements describe why your financial health has worsened due to the Coronavirus/COVID-19? Base: US Caregivers n=409
Q21. Since the Coronavirus/COVID-19 pandemic began, are you spending more, less or the same amount of money for each of the following? Base: US Caregivers n=750

Top Reasons Why Caregivers’ Financial Health Has Worsened Due to the Pandemic (among caregivers whose financial health worsened)

- More of my money is going toward supplies and resources I need to provide care (37%)
- Government/social service/insurance provided financial support is not enough to cover my expenses (23%)
- My professional/paid working hours were reduced/cut back (22%)
- I’ve had to reduce my professional/paid working hours because of my caregiving duties (18%)
- My salary was reduced (18%)
- I lost my job (16%)

Since the beginning of the pandemic, caregivers are spending more money on:
- Food (63%)
- Household bills (47%)
- Medical equipment (e.g. PPE) (46%)

54% of caregivers say the pandemic has worsened their financial health.
Social relationships are suffering; Peer connection is an effective way to improve emotional health, but few are doing it.

50% of caregivers say being a caregiver negatively impacts their relationship with friends.

Although 71% say connecting with other caregivers who are going through similar situations always makes them feel better.

Only 15% talk to other caregivers (online, in-person, or over the phone) as an activity to improve their emotional/mental health.

There are other people out here doing the same thing. Reach out to us! And get the support you need.”

– 36-year-old Male taking care of someone with Alzheimer’s
Lack of sleep and exercise, poor diet, and postponing their own medical appointments are worsening caregivers’ physical health.

44% of caregivers say the pandemic has worsened their physical health.

Top Reasons Why Caregivers’ Physical Health Has Worsened Due to the Pandemic
(among caregivers whose physical health worsened)

- I am lacking sleep: 62%
- I have postponed my own medical appointments: 45%
- I’m exercising less: 41%
- I have adopted unhealthy eating habits: 40%
- I can’t afford nutritious food: 25%
- I can’t afford medication and vitamins/supplements I need: 17%

Q12. In general, do you feel the Coronavirus/COVID-19 has improved or worsened each of the following aspects of your health/wellbeing? Base: US Caregivers n=750
Q19. Now, please select from the below list, which, if any, of the following statements describe why your physical health has worsened due the Coronavirus/COVID-19? Base: US Caregivers n=327
IV: Inequities in Caregiving

“My work hours have been reduced. So I spend more time taking care of my loved one. I also have to work much harder and longer doing more things for him because I am trying to protect him from getting the coronavirus.”

– 64-year-old Hispanic or Latina Female caring for someone with Alzheimer’s
While all caregivers, including men, experience challenges in caregiving, women face disproportionate hurdles

**WOMEN CAREGIVERS**

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/yr) than men caregivers (56% vs. 36%, respectively).
- Women caregivers are more likely than men to say they have never received support from private companies (84% vs. 75% men caregivers), local communities (72% vs. 64% men caregivers), among others.

Women caregivers have more on their plate
- Women caregivers are more likely than men to spend an average of 41+ hours a week on caregiving now (25% vs. 18% men caregivers).
- Women tend to have more caregiving responsibilities in general than their male counterparts like providing emotional support (80% vs. 70% men caregivers) and preparing meals (73% vs. 63% men caregivers).

Access to social services and financial tools are very important resources for women caregivers
- Women say more financial tools from the local/state government (56%) and receiving increased access to social services (53%) to ensure they are able to properly provide the care needed is very important, in comparison with 47% and 43% of men caregivers who say this, respectively.
Women encounter greater economic hurdles, increased reliance and report receiving less support from institutions

56% of women caregivers are low income^ (Men caregivers: 36%)

74% of women caregivers are concerned if they get COVID-19, there won’t be anyone to take care of the person they care for (Men Caregivers: 66%)

48% of women caregivers say “the person I care for is relying on me more than ever” (Men Caregivers: 38%)

Caregivers who say these organizations are not providing enough support for them

- The federal/national government: 56% (Women: 64%, Men: 56%)
- The local/state government: 52% (Women: 61%, Men: 52%)
- Insurance companies: 43% (Women: 59%, Men: 43%)
- Local communities: 48% (Women: 56%, Men: 48%)
- Social services/care professionals: 43% (Women: 56%, Men: 43%)
- Private companies in general: 44% (Women: 53%, Men: 44%)
- Non-profit organizations/advocacy groups: 42% (Women: 52%, Men: 42%)
- Healthcare professionals: 37% (Women: 51%, Men: 34%)
- My employer: 34% (Women: 44%, Men: 44%)

^Low income is referred to as having a household income of less than $49,999.

*References to women are specific to female caregivers, similarly men callouts are specific to male caregivers.

Q14. Which of the following statements is true for you as it relates to how COVID-19 pandemic has impacted your ability to provide care? "The person I care for is/are relying on me more than ever before? Base: Female n=499, Male n=250

Q26. How concerned are you about each of the following as it relates to caregiving? NET: Concerned = 'Very concerned', 'somewhat concerned'. Base: Female n=499, Male n=250

Q27. In your opinion, are caregivers/carers currently receiving too much, the right amount, or not enough support from each of the following entities? NET: Not receiving enough support. Base: Female n=499, Male n=250

MRK_INC_US. Please indicate your annual household income before taxes? Net: Low Income (<$50,000) Base: Female n=499, Male n=250
Women caregivers carry greater responsibility

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.

*References to women are specific to female caregivers, similarly men callouts are specific to male caregivers.

Q8. On average, how many hours did/do you spend on caregiving during each of the following timeframes? Base: Female n=499, Male n=250

Q6. What are your primary responsibilities as a caregiver/carer? Select all that apply. Base: Female n=499, Male n=250

Q21. Since the Coronavirus/Covid-19 pandemic began, are you spending more, less or the same amount of money for each of the following? Base: Female n=499, Male n=250

* Women Caregivers
* Men Caregivers

- Providing emotional support: 80% (Female), 70% (Male)
- Preparing meals: 73% (Female), 63% (Male)
- Managing doctor appointments: 71% (Female), 58% (Male)
- Advocating for the person’s care: 49% (Female), 38% (Male)

- Spending 30+ hours a week on caregiving responsibilities:
  - Before the pandemic: 28% (Female), 18% (Male)
  - During the peak of the pandemic: 42% (Female), 32% (Male)
  - Now: 42% (Female), 31% (Male)

66% of women caregivers are spending more money on food during the pandemic, compared to 58% of men.
Improved access to care, more financial tools, and employer support can bridge needs of women caregivers

**Access & Accessible Care**

- **65%**
  - Access to masks, gloves & other personal protective equipment (PPE) for caregivers is very important
  - (Men caregivers: 52%)

- **53%**
  - Its very important they receive increased access & availability for social services/care
  - (Men caregivers: 43%)

**Education & Financial Tools**

- **57%**
  - Strongly agree that there needs to be more mental/ wellness resources readily available for caregivers
  - (Men caregivers: 46%)

- **56%**
  - More financial tools to support unpaid caregivers/carers from the local/state government is very important
  - (Men caregivers: 47%)

**Employer Support**

- **54%**
  - Strongly agree employers should provide additional flexibility policies and support for caregivers/carers
  - (Men caregivers: 46%)

*References to women are specific to female caregivers, similarly men callouts are specific to male caregivers.

Q28. As you continue to be a caregiver, how important will each of the following items be in ensuring you are able to properly provide the care needed? Base: Female n=499, Male n=250

Q29. How much do you agree, if at all, with each of the following statements? Base: Female n=499, Male n=250
In a similar manner, diverse caregivers also face disproportionate struggles.

### Racial/Ethnic Minority Caregivers

**Racial/ethnic minority caregivers are more likely to have had their salary reduced**
- 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.

**Racial/ethnic minority caregivers have high concern of COVID-19 infection risks**
- 91% of racial/ethnic minority caregivers say they are concerned about the second wave of the Coronavirus/COVID-19 virus in general (vs. 86% of white caregivers).

**Racial/ethnic minority caregivers desire greater support and access to resources to help them combat COVID-19**
- 62% say its very important they receive increased access and availability for health care services (vs. 50% of white caregivers).
- 56% say more information and education on how I can best protect myself from the COVID-19 while still being a caregiver is very important (vs. 40% of white caregivers).

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Racial/ethnic minority caregivers included all nonwhite caregivers, which consisted of ‘Black or African American’ n=70, ‘Asian/Pacific Islander’ n=27, ‘Native American, Alaska Native, Aleutian’ n=5, Hispanic or Latino (White or Caucasian) n=45; Hispanic or Latino (Black or African-American) n=6, Hispanic or Latino (all other races/multiple races) n=18, Other n=2. Base: Total Racial/Ethnic Minority Caregivers n=180; Total White Caregivers n=570

Q20. How concerned are you, if at all, about each of the following as it relates to caregiving? Concerned NET: Base: Racial/Ethnic Minority Caregivers n=180; White Caregivers n=570
Q25. How concerned are you, if at all, about each of the following as it relates to caregiving? Concerned NET: Base: Racial/Ethnic Minority Caregivers n=180; White Caregivers n=570
Potentially due to current financial hardships, racial/ethnic minority caregivers have reshaped their perspectives on having a family.

28% Had their salary reduced (among caregivers whose financial health worsened due to the pandemic)

(White caregivers: 14%)

46% agree the COVID-19 pandemic has caused them to rethink ever having a child.

(White caregivers: 36%)
They are also more concerned about.....

**Infections & Re-openings**

91% of racial/ethnic minority caregivers say they are concerned about the second wave of the Coronavirus/COVID-19 virus in general.

(White Caregivers: 86%)

**Innovation Decline**

68%

Focus on the coronavirus will lead to a decline in new innovations and treatments for the condition the person/people I care for has/have.

(White Caregivers: 57%)

**Access to Supplies**

27% of racial/ethnic minority caregivers say they are very concerned they will not be able to access the medication and supplies needed to provide proper care.

(White Caregivers: 19%)

Q26: How concerned are you, if at all, about each of the following as it relates to caregiving? Concerned NET Base: Racial/Ethnic Minority Caregivers n=180; White Caregivers n=570
Improved access, education and employer support can bridge needs of diverse caregivers

Access & Accessible Care

- **71%**
  - Access to masks, gloves & other personal protective equipment (PPE) for caregivers is very important
  - (White caregivers: 57%)

- **62%**
  - Its very important they receive increased access & availability for health care services
  - (White caregivers: 50%)

Education & Guidance

- **64%**
  - Strongly agree that there needs to be more mental/wellness resources readily available for caregivers
  - (White caregivers: 50%)

- **56%**
  - More information and education on how I can best protect myself from COVID-19 while still being a caregiver is very important
  - (White caregivers: 40%)

- **55%**
  - Help navigating the health and social services/care systems to ensure I am getting all the benefits I am entitled to is very important
  - (White caregivers: 46%)

Employer Support

- **50%**
  - Carer-friendly workplaces that understand and respond to my needs as a carer is very important
  - (White caregivers: 39%)

Q28. As you continue to be a carer, how important will each of the following items be in ensuring you are able to properly provide the care needed? 'NET: Very Important' Base: Racial/Ethnic Minority Caregivers n=180; White Caregivers n=570
Q29. From the list below, which, if any, of the following statements describe why your emotional/mental health has worsened due to the coronavirus? 'NET: I am anxious about balancing my paid job/work and caregiving responsibilities.' Base: Racial/Ethnic Minority Caregivers n=180; White Caregivers n=570
Q30. How much do you agree, if at all, with each of the following statements? Base: Racial/Ethnic Minority Caregivers n=180; White Caregivers n=570
“See us. Hear us. Care about our stories and our pain!”

— 36-year-old female caring for someone with an ongoing/long-term cognitive/mental condition

Della Phillips (caregiver), with her mother Audrey and daughter

V: Path to Solutions
The pandemic has fostered distrust, leaving many caregivers highly apprehensive about infection and re-openings

<table>
<thead>
<tr>
<th>Top concerns for caregivers</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The second wave of the Coronavirus/COVID-19 in general.</td>
<td>87%</td>
</tr>
<tr>
<td>Increase in Coronavirus/COVID-19 infections from re-openings.</td>
<td>82%</td>
</tr>
<tr>
<td>The person I care for is/are going to get the Coronavirus/COVID-19 and be at risk of dying.</td>
<td>74%</td>
</tr>
<tr>
<td>I will need to spend more time providing care in the future because the Coronavirus/COVID-19 has made me distrust assisted living, retirement communities and nursing homes.</td>
<td>72%</td>
</tr>
<tr>
<td>I am going to get the Coronavirus/COVID-19 and then there won't be anyone to take care of the person/people I care for.</td>
<td>71%</td>
</tr>
<tr>
<td>I am going to get the Coronavirus/COVID-19 and infect the person/people I care for.</td>
<td>70%</td>
</tr>
</tbody>
</table>

Q26. How concerned are you, if at all, about each of the following as it relates to caregiving? Base: US Caregivers n=750
Concerns extend beyond the immediate health threat that COVID-19 poses to caregivers

66%
Focus on the Coronavirus/COVID-19 will lead to less medical resources available to treat the condition the person/people I care for has/have.

66%
I am not going to be able to afford to provide proper care.

60%
I am not going to be able to access the medication and supplies needed to provide proper care.

Concerns for caregivers

67%
I will have to work full time remotely while also caregiving for the foreseeable future.

56%
I will lose my job because of the time commitment needed as a caregiver/carer.

56%
I will need to use more technology and digital tools to manage care properly.
Caregivers nearly unanimously feel invisible and unsupported, especially by the government

94% say the important role caregivers have is not widely recognized by society

Caregivers Are Not Receiving Enough Support From:

- The federal government: 61%
- The local/state government: 58%
- Insurance organizations: 54%
- Local communities: 53%
- Social services/care professionals: 52%
- Private companies: 50%
- Non-profit organizations/advocacy groups: 49%
- Healthcare professionals: 46%
- My employer*: 39%

*Asked among employed (full-time, part-time, self-employed) US caregivers. Base: Employed US Caregivers n=415
Q27. In your opinion, are caregiver/carers currently receiving too much, the right amount, or not enough support from each of the following entities? Base: US Caregivers n=750
Q29. How much do you agree, if at all, with each of the following statements? Agree Summary. Base: US Caregivers n=750

Embracing Carers is supported by EMD Serono
Caregivers need help to provide care, and solutions can be found in public and private settings

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employers</td>
<td>94%</td>
<td>of caregivers agree employers should provide additional flexibility policies and support for caregivers/carers.</td>
</tr>
<tr>
<td>Governments</td>
<td>94%</td>
<td>of caregivers agree the health and social services/care system needs to do more to support caregivers/carers.</td>
</tr>
<tr>
<td>Insurers</td>
<td>80%</td>
<td>of caregivers agree insurance organizations (e.g. care insurance/care insurance and SHI, health care insurance) should do more to support me as a caregiver/carer.</td>
</tr>
<tr>
<td>Social Services</td>
<td>95%</td>
<td>of caregivers agree there needs to be more mental/wellness resources readily available for caregivers/carers.</td>
</tr>
</tbody>
</table>

83% of caregivers say the government should do more to support me as a caregiver/carer.

*Asked among employed (full-time, part-time, self-employed) US caregivers. Base: Employed US Caregivers n=415
Q24 To what extent, if at all, do you agree with the following statements? Agree Summary. Base: US Caregivers n=750; Base: Employed NET n=415
Q29 How much do you agree, if at all, with each of the following statements? Agree Summary. Base: US Caregivers n=750
Conclusion & Opportunities

Arnold Schnittger (caregiver) and his son Nico
Conclusion: The pandemic has dramatically exacerbated and accelerated the pain points of unpaid caregivers

I. Rising Demands

The burden on family caregivers grows as the pandemic continues. The status quo is neither sustainable nor acceptable.

II. Changed Responsibilities

Unpaid caregivers have been forced to navigate the new demands arising from the pandemic on their own. They need assistance, and they need it now.

III. The Toll on Caregivers

Many caregivers are overwhelmed, facing depression and burnout as the pandemic continues. Financial, tactical and emotional support are required to sustain them.

IV. Inequities in Caregiving

The pandemic has worsened the added challenges facing women caregivers and racial/ethnic minority caregivers. Addressing these disparities is critical.

V. Path to Solutions

Caring for the elderly, the disabled and the chronically ill is a societal responsibility. All sectors must act now to dramatically enhance support for America’s unpaid caregivers.
Societal opportunities to support caregivers: *Short-term*

**Short-Term Relief & Actions for Caregivers**

- Customize language, communications, channels and solutions for newer entrants to caregiving, including parents of small children and younger generations (Gen Z, Millennials)

- Provide support that alleviates the top responsibilities impacting caregivers (e.g. meal kits for preparing meals, cleaning services for home maintenance, transportation services for travel to appointments, etc.)

- Offer free/subsidized internet usage; Target older caregivers with greater resources, trainings and guides to enhance their telehealth and technology experiences

- Aid financially by distributing PPE and providing access to resources (e.g. meal kits, grocery gift cards, etc.), as well as cleaning and transportation services

*Greg Smith (caregiver) and his mother, Lyn.*
## Societal opportunities to support caregivers: Long-term

### Long-Term Solutions to Support Caregivers

<table>
<thead>
<tr>
<th>Emotional/Mental Well-Being</th>
<th>Financial Well-Being</th>
<th>Physical Well-Being</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provide respite care services that are flexible and easy to secure</td>
<td>• Provide ongoing access to PPE to eliminate concerns of having access to resources</td>
<td>• Deliver sleep aids, such as teas, vitamins, meditation apps, etc. that support better sleep health</td>
</tr>
<tr>
<td>• Create and promote points of social connection with peer caregivers</td>
<td>• Organize a database or listing of job postings with flexible hours for caregivers who are seeking new opportunities</td>
<td>• Offer free virtual exercise classes that caregivers can take at their leisure</td>
</tr>
<tr>
<td>• Provide and promote advice/therapy hotlines for real-time emotional support</td>
<td>• Provide employee legal services that aid caregivers’ ability to advocate for flexible accommodations from their employer(s)</td>
<td>• Share healthy recipes, tips and suggestions in newsletters and materials</td>
</tr>
<tr>
<td>• Share motivational, uplifting stories that help caregivers feel advocated for</td>
<td>• Advocate for policies that support financial relief for caregivers (direct payments, tax credits, etc.)</td>
<td>• Identify participating doctors, health centers, etc. with early and late hours to accommodate caregiver schedules</td>
</tr>
<tr>
<td>• Offer and promote quality mental health aid, with top-tier providers, that is easy to navigate and at no cost</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Actionable opportunities for public stakeholders

### Local, State & Federal Governments

- Develop partnerships with private companies to provide PPE to caregivers at a reduced or no cost
- Work on bipartisan, legislative solutions like amending federal tax policy to provide greater (and uniform) support for unpaid caregivers, potentially including tax credits (perhaps tied to the hours spent caregiving), enhanced deductibility for the direct costs of caregiving, etc.
- In the same way that subsidies are provided to those who are unemployed or direct payments (through SSI) to the elderly, the federal government should consider subsidy payments to help underwrite the cost/time associated with caregiving
- Create a national mandate for paid family leave for unpaid caregivers
- Make respite programs under the National Family Caregiver Support Program and the Lifespan Respite Care Act of 2006 easier to access with more availability
- Increase awareness of the caregiving experience through research and storytelling, advocate for caregiver needs with policymakers

### Public Sector

- Develop local caregiver support networks to enhance and formalize local connections between caregivers
- Training for new and long-term caregivers (and those who support caregivers) in managing and avoiding burnout
## Actionable opportunities for private stakeholders

### Private Sector
- Partner with local grocery stores and meal delivery services to ensure caregivers obtain easy, affordable access to home delivery of food and cleaning products.
- Partner with local hospitals to provide training on effective access to telehealth resources.
- Partner with local cable and other internet providers to ensure caregivers obtain access to free and/or affordable WIFI.
- Incentivize employers to promote healthy work-life balance through tax credits, public paid family and medical leave, and other similar programs.

### Employers
- Develop support programs for employees who are unpaid caregivers—giving them flexible working hours, paid family medical leave, etc.
- Identify internal champions that employees can look to who are interested and willing to support caregiving in the workplace and play an active role in celebrating and creating a dialogue, as well as a supportive culture around caregiving.

### Insurers
- Provide flexible benefits and financial payment options for caregivers.
- Offer customized resources (e.g. newsletter, group sessions, etc.) specific to the needs of caregivers.
- Offer counseling programs that are covered by plans to help caregivers coping with burn out, stress, etc.
- Cover the cost of PPE needed by caregivers as the pandemic continues.
When the pandemic hit the United States, countless businesses shuttered their doors and families found themselves under stay-at-home mandates and quarantine orders. These new pressures made the care journey more challenging, both for caregivers living with someone in their care and those caring from a distance. Younger adults and parents were especially likely to step into caregiving roles, despite having to manage their own, interrupted obligations.

Caregivers haven’t been alone in experiencing the pressures of the pandemic but many faced pressures, demands and time commitments that others may not understand. As health and social care providers move to rapid responses to control COVID-19, caregivers must navigate fast-changing care delivery models, learn new telehealth and technology, provide emotional support despite their own emotional needs, and handle increased responsibilities at home—all at once.

The question remains: Who is caring for the caregiver? The caregivers in this survey reported that they often sacrifice their own health and well-being for the sake of people they love. They deal with emotional isolation. Financial strife hits hard as unemployment spikes and salaries are imperiled. Many lack the time to care for their own physical and emotional health. These challenges are even more significant among women and racial/ethnic minority caregivers, who encounter inequities throughout the job market and the economy. Add it all up, and the United States faces a deep societal problem: American caregivers are undercounted, unheard, struggling, and all but invisible.

The question ahead, is what are we going to do about it? Now more than ever, federal and state governments, public entities, the private sector and everyday Americans all have a role to play in addressing that problem. Caregivers should not have to face these hardships and inequities alone. As a society, we can help them, together.
Next steps

In collaboration with Embracing Carers, EMD Serono is committed to:

• Convening key advocacy, government and private sector stakeholders to identify potential priority next steps and strategies to support caregivers in 2021

• Working with stakeholder groups to identify potential sources, channels and opportunities to ensure caregivers have access to PPE and other needed pandemic preparedness supplies

• Urging Department of Health and Human Services (HHS) and Centers for Disease Control (CDC) to ensure caregivers are included in Tier One (alongside Health Care Providers in Long-Term Care Facilities) as among those who have earliest access to approved COVID-19 vaccine(s)

• Releasing more data! In January 2021, Embracing Carers will release the Global Carer Well-Being Index which focuses in on 12 countries. The global report will provide an opportunity for comparative analysis, emphasize key learnings and focus attention on improving the well-being of caregivers around the world.
Resources & Acknowledgments

To learn more about caregiving and resources available for caregivers, as well as those advocating for caregivers, please visit our partner organizations websites.

Embracing Carers success comes through a collaborative effort by many. Thank you to the Embracing Carers partner organizations for their continued support and counsel on the 2020 Carer Well-Being Index. The completion of this research would not have been accomplished without the support of:
Appendix

Deborah Spencer (caregiver) and her daughter Dominique
Detailed research methodology

Merck KGaA, Darmstadt, Germany (operates its biopharmaceutical business in the U.S. and Canada as EMD Serono) has conducted proprietary research to determine the adverse and disproportionate affects the Coronavirus pandemic has had on unpaid caregivers around the world, including their economic, physical and psychological well-being. Building on the five global priorities established in the Global State of Care report, Merck KGaA, Darmstadt Germany/EMD Serono and its Embracing Carers partner organizations commissioned this research to give a clear mandate to leaders within the public and private sector of the concerns of unpaid caregivers and key solutions to best support them.

In partnership with a third-party global leader in multinational market research, a survey was fielded online from September 3-24, 2020 among 750 unpaid caregivers (or “carers”) in the United States. Unpaid caregivers were defined as those who are caring for someone with a long-term illness, physical disability, or cognitive/mental condition (including cancer, Multiple Sclerosis, Parkinson’s Disease, Dementia, Alzheimer's, Spinal cord injury, Muscular Dystrophy, cognitive/mental condition, Congestive Heart Failure, etc.). Outgoing sample collected was balanced to U.S. Census to then 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 United States of America total for the unpaid caregiver population has an estimated margin of error of +/- 3.6 percentage points. The survey length was approximately 20-25 minutes.
Demographic breakout of the sample surveyed in the United States

**Demographic breakout of sample (n=750)**

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>66%</td>
</tr>
<tr>
<td>Male</td>
<td>33%</td>
</tr>
<tr>
<td>Location</td>
<td></td>
</tr>
<tr>
<td>Urban/Suburb</td>
<td>83%</td>
</tr>
<tr>
<td>Rural</td>
<td>17%</td>
</tr>
<tr>
<td>Employment (Full/Part Time)</td>
<td>55%</td>
</tr>
<tr>
<td>Parent (under 18 only)</td>
<td>45%</td>
</tr>
<tr>
<td>Generation</td>
<td></td>
</tr>
<tr>
<td>Millennial</td>
<td>40%</td>
</tr>
<tr>
<td>Gen X</td>
<td>31%</td>
</tr>
<tr>
<td>Baby Boomer</td>
<td>22%</td>
</tr>
<tr>
<td>Gen Z*</td>
<td>7%</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>83%</td>
</tr>
<tr>
<td>Black or African American*</td>
<td>12%</td>
</tr>
<tr>
<td>Hispanic*</td>
<td>11%</td>
</tr>
<tr>
<td>Other*</td>
<td>7%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Lower (Less than high school graduate)*</td>
<td>3%</td>
</tr>
<tr>
<td>Middle (Graduated High School)</td>
<td>61%</td>
</tr>
<tr>
<td>Higher (Bachelor’s degree and above)</td>
<td>36%</td>
</tr>
<tr>
<td>Income</td>
<td></td>
</tr>
<tr>
<td>Low (Under 50K)</td>
<td>50%</td>
</tr>
<tr>
<td>Medium (50K - 100K)</td>
<td>37%</td>
</tr>
<tr>
<td>High (100k+)</td>
<td>13%</td>
</tr>
</tbody>
</table>

Total Respondents in the United States: 750

*Base size is less than 100 and/or percentage is less than 11% and should be used for directional purposes only
Detailed breakdown of conditions and people being cared for

About the people they care for (n=750)

Gender of the Person they Care for

- Female: 56%
- Male: 51%

Age of the Person they Care for

- Less than 18: 11%
- 18-24*: 3%
- 25-34*: 7%
- 35-44*: 6%
- 45-54*: 10%
- 55-64: 19%
- 65+: 50%

Top Relationships with the Person(s) they Care for

- Parents: 41%
- Child: 13%
- Spouse: 12%
- Grandparent: 9%
- Partner: 8%

Top Conditions of the Individual(s) They Care for

- 31%: Ongoing/long-term cognitive/mental condition
- 30%: Alzheimer's/Dementia
- 25%: Physical disability

*Base size is less than 100 and/or percentage is less than 11% and should be used for directional purposes only

Total Respondents in the United States: 750