



How Crisis Impacts the Way We Care: Understanding COVID-19's Impact on Family Caregivers & Lessons for Future Challenges

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Introduction

The COVID-19 pandemic has brought to the forefront the gaps in information to help families navigate the caregiving journey. Despite numerous national resources, there is no centralized source of information to help family caregivers, researchers, and providers find information that they might need to navigate the caregiving experience.

Take Care Community, a combined effort by the National Alliance for Caregiving and Adira Foundation, is a new, online digital platform designed to gather resources from the caregiving community with the goal of creating a clearinghouse of credible resources to help family caregivers and the professionals who support them. Caregivers and other stakeholders will be able to search and find resources to navigate the siloed systems of support across the health care, social care, and long-term care sectors.

Co-founded by Adira Foundation and the National Alliance for Caregiving, Take Care Community is led by a multi-stakeholder Steering Committee with expertise in chronic disease. Together, these organizations have built the current digital space for resource submissions and developed a framework that reflects the reality of caregiving during a crisis and beyond that will ensure the content of Take Care Community improves and grows in the direction people need.

The Caregiving During COVID-19 Framework is a two-part infographic that presents (1) the pressure points caregivers face during a crisis and (2) interventions to support them. The framework's purpose is to inform policymakers, influencers, researchers, philanthropists, innovators, and other key stakeholders that COVID-19 has exposed the fragility and unsustainability of

current caregiving paradigms. Written in the perspective of a caregiver to improve these decisionmakers' understanding of the caregiving experience, the framework tells a story of the systematic and personal challenges caregivers may face day-to-day and the solutions that can protect them and allow them to thrive. These solutions are also outlined in the "Call to Action" section of this paper on page 4.

It is important to note that while the framework was developed in response to the COVID-19 healthcare crisis, the pressure points and interventions identified are relevant to the caregiving experience in general, and not just during a crisis. The solutions outlined in the framework and in this paper cannot be carried out by caregivers themselves; these solutions need to be implemented on a systematic level by policymakers, influencers, researchers, philanthropists, innovators, and other key decisionmakers. While we don't have all of the answers to caregivers' challenges, this is a starting point to understanding their experience and educating those in power that impact the caregiving experience. In the spirit of collaboration, we encourage you to explore the framework and this accompanying paper and share your feedback at www.takecare.community/the-framework. We look forward to adapting and changing this framework as we learn more about caregivers and their needs.

Background

Prior to COVID-19, national research estimated that nearly 53 million Americans are caring for a friend or family member with a health care need or functional disability.¹ Despite advances in technology in the last five years, and despite new efforts to improve the delivery of care under the Affordable Care Act and other programs, those who help with coordinating care for the person they support find it more difficult than in 2015 to access the health and long-term services and supports systems.²

This difficulty in coordinating care as reported in NAC and AARP's Caregiving in the U.S. 2020 study was fairly universal – impacting all age groups under age 75, all genders, and income groups, regardless of whether the caregiver felt they had a choice, whether they worked, and irrespective of where they live.

When the COVID-19 pandemic hit the United States, new challenges were introduced into an already taxing and complicated care journey. Research from the University of Pittsburgh in the summer of 2020 illustrated this challenge, as one caregiver described, “There’s just no voice for us.”³ Key findings in that work, capturing perspectives from 3,500 family caregivers and non-caregivers, were clear:

- Four out of ten family caregivers said the pandemic worsened their mental health (43%) and their finances (43%).
- Nearly a third (27%) said their health was worse than before the pandemic and one in three (31%) reported that their ability to access health care was worse than before the pandemic.
- Families worried about having enough food and being able to pay for food.

As the United States struggled with its response to the COVID-19 pandemic, the ongoing stressors to the health and social care systems laid bare existing challenges for family caregivers across the lifespan. Research from the Rosalynn Carter Institute for Caregiving released in October 2020 found that most caregivers experienced a threefold increase in stress associated with caregiving.⁴ Caregivers' ability to access usual supports – such as adult day care or respite, coaching or counseling, assistance from friends, family, or neighbors, in-home care, and support groups – were disrupted by the pandemic. As the research done at the University of Pittsburgh revealed, caregivers continued to experience the same threats to their basic human needs, reporting fear about keeping themselves or others safe from COVID-19, increased worries about access to food, and worsening isolation.⁵

A multi-national survey of caregiver needs led by the Embracing Carers initiative examined caregiver well-being in the United States and echoed the impact of COVID-19 in family caregivers. Fielded in the fall of 2020 and released in November, the report mirrored the findings of other research in the United States and around the world:

- **Rising demands on caregivers**, including younger populations and parents “sandwiched” between care responsibilities, sometimes spending more than 40 hours a week on care activities;
- **Changed responsibilities**, including being asked to manage new technologies and requiring emotional support despite lack of access to respite and support groups;
- **Costs of caregiving to the family**, as three out of four (72%) caregivers said they felt “more burnt out than ever before” and reported worsening emotional/mental health (68%), worsening financial health (54%), and impacts on physical health (44%) such as lack of sleep (62%), postponed medical appointments (45%), and not being able to afford nutritious food (25%); and
- **Heightened inequities**, as women were more likely to be the sole support for the person in their care and to rely on government assistance, and as caregivers in racial or ethnic minorities indicated that the COVID-19 pandemic has worsened their financial situation, with 46% indicating that they are rethinking ever having a child due to the experience.⁶

¹AARP and National Alliance for Caregiving. (2020, May). Caregiving in the United States 2020. More at <https://www.caregiving.org/caregiving-in-the-us-2020> and <https://doi.org/10.26419/ppi.00103.001>.

²In 2020, 31% of caregivers who coordinate care found it very difficult or somewhat difficult, compared to 23% in 2015.

³University of Pittsburgh. (2020, July). Effects of Covid-19 on family caregivers: A community survey from the University of Pittsburgh. http://www.caregiving.pitt.edu/wp-content/uploads/2020/07/Full_Report_Final.pdf.

⁴Rosalynn Carter Institute for Caregiving. (2020, October). Caregivers in crisis: Caregiving in the time of COVID-19. <https://www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-Report-October-2020-10-22-20.pdf>.

⁵University of Pittsburgh. (2020, July). Effects of Covid-19 on family caregivers: A community survey from the University of Pittsburgh. http://www.caregiving.pitt.edu/wp-content/uploads/2020/07/Full_Report_Final.pdf. See also NORC at the University of Chicago. (2021, January). Needs assessment and environmental scan report: Maintaining physical and mental well-being of older adults and their caregivers during public health emergencies. <https://www.norc.umd.edu/PDFs/Maintaining%20Physical%20and%20Mental%20Well%20Well/ESandNAReportNarrative.pdf>.

⁶Embracing Carers, and initiative of EMD Serono. (2020). The U.S. carer well-being index: Who cares for caregivers? Perspectives on Covid-19 pressures and lack of support. https://www.embracingcarers.com/content/dam/web/healthcare/corporate/embracing-carers/home/document/United_States_Carer_Well-Being_Index_Report_FINAL_11.17.20.pdf

Framework Purpose

The purpose of the framework is to alert and inform policymakers, influencers, researchers, philanthropists, innovators, and other key stakeholders that COVID-19 has exposed the fragility and unsustainability of current caregiving paradigms.

Drawing from themes identified in national and global research, the framework seeks to provide – at a glance – a quick means to understand the additional impact that an external, existential crisis such as the pandemic can create. By spotting the key pressure points for caregivers, the framework also aims to identify gaps in resources and to spur designers, researchers, and policymakers to address the need ahead of the new crisis.

Finally, the framework offers a starting point for a new online resource, the Take Care Community, which will centralize curated information for caregivers and those who work with caregivers, making it easier for families to navigate their experience based on their functional needs. More than ever, caregivers need high quality, easy to access resources that reduce decision fatigue, and allow them to better engage with the supports they need to improve their quality of life.

External, existential “pressure points” that threaten the safety and wellbeing of family caregivers



Potential solutions for caregivers regardless of main problem of illness requiring care

The framework seeks to provide – at a glance – a quick means to understand the additional impact that an external, existential crisis such as the pandemic can create.

Call to Action

While the first part of the framework puts forth the challenges caregivers face during a crisis, the second part of the framework seeks to point out the interventions that could support individuals on their caregiving journey and protect them from these pressure points. The interventions, identified below, should be implemented on a systematic level by policymakers, influencers, researchers, philanthropists, innovators, and other key stakeholders.

1

Prepare caregivers for caring.

State and local advocates, reach out to the caregivers in your community to make sure they know about the resources available to them, such as respite programs and educational tools.

Providers, make sure caregivers are properly trained and ready to take on care at home, especially when care involves complex medical tasks.

2

Include caregivers on the care team.

Providers, equip caregivers with the knowledge and training they need to feel empowered on the care team.

3

Connect caregivers with supports.

Policymakers, you can help caregivers find support by protecting and expanding state and local support programs for caregivers and families.

Employers, protect caregivers in the workplace by offering benefits such as paid family leave and flexible schedules.

How We Created This Framework

This framework was developed from community input given through a series of interviews and town hall events. Subject-matter experts, patient and caregiver advocates, and public and private organizations working in caregiving contributed their expertise, knowledge and perspectives as the framework was created and refined. A series of meetings with the stakeholders were held over the past nine months and included:

Spring 2020

Development of the COVID-19 caregiving map and review with the National Alliance for Caregiving [Board of Directors](#) and more than 60 organizational [Members](#)

Summer 2020

Framework workshoping with the three NAC Collaboratives, including:

The Research Collaborative, a peer-to-peer network of policy and academic researchers from more than 40 institutions working on caregiving, family support, and care issues across the lifespan and including pediatric, adult care, and geriatric focus areas;

The Advocacy Collaborative, including state and local caregiving coalition advocates from approximately 30 localities and national coalition leaders in health, aging, and disability; and

The Innovation Collaborative, including technology designers, payers, employers, and other thought-leaders interested in the translation of research to practice.

Fall 2020

Framework workshoping with person- and family-centered communities, including:

A community town hall for family caregivers, open to the public and with over 100 attendees representing caregiving experiences in aging, cancer, rare disease, mental illness, central nervous system disorders, and other care needs; and

A global town hall featuring researchers and executive leadership from non-governmental organizations from around the world, including North America, South America, Africa, Europe, Asia and the Pacific, and global coalitions such as Embracing Carers, the International Alliance of Carer Organizations, the World Dementia Council, Eurocarers, and others.

Finally, this framework reflects the insights and guidance of our project Steering Committee: [The Gerontological Society of America](#), [National Health Council](#), [Mental Health America](#), and the Clara Health public health initiative, [World Without Covid](#).

Get Involved & Share Your Insights

In discussing the framework with this network of experts, caregivers and professionals have raised that many of the challenges identified are not unique to the COVID-19 experience. Furthermore, a framework on its own cannot affect change. We anticipate using this framework as a starting point to centralize information for caregivers and professionals based on their areas of need and across fractured systems of support. Ideally, the Take Care Community will offer a collaborative space for caregivers, professionals, advocates, providers, and other stakeholders to share resources and knowledge to support caregivers during crisis.

Sharing Feedback and Resources

The framework is composed of two parts that, together, highlight the challenges caregivers face during a crisis, as well as the basic needs of caregivers.

The first framework will be used to communicate to policymakers, innovators, and researchers the pressure points that friend and family caregivers have faced during the COVID-19 pandemic and recovery.

The second framework will be used for the Take Care Community website, as a content map to assist with the identification of services, research, and programs that can help family caregivers navigate crisis. Rather than aggregate resources by a specific disease or condition, the Take Care Community site will offer concise, curated content, reviewed by nonprofit and NGO experts, and informed by the lived experiences of people who care for someone with a healthcare need or disability.



Published resources should meet the following criteria:

- Credible author or source
 - Check if they are affiliated with an organization or an individual
 - Check their public platform (i.e. public reviews, social media account, etc.)
- Focused primarily on the family caregiver
- Fulfills project objectives by addressing individual caregiver needs for support and resources in at least one of the following ways:
 - Getting past the gate – realizing caregivers are “more than visitors”
 - Near or far – helping physically distant caregivers
 - When caregiving ends – grief, bereavement, advanced care
 - Caring for the caregiver themselves
 - Managing loneliness, isolation
 - Managing household safety and security (finances incl.)
 - School/work
 - Finding hope (scientific opportunities, clinical trials incl.)

Categorizing resources once vetted:

Once resources have been vetted, they will be categorized based on page 2 of the COVID-19 Caregiving Framework, which ground resources by **activity of care**. This will be used as a guide for the development of this Wikipedia-style resource page by helping us prioritize what types of content needs to get out to caregivers and categorize that content into different needs-areas (i.e. self-care, care coordination, medical care, etc.).

Within each category, different icon will appear next to the listed resources to indicate whether the resource has a fee, comes from an organization with a commercial interest, and the primary audience of the resource (i.e. professionals, caregivers, etc.).



For more information on how you and your family can be safe in the time of Covid-19, please visit the CDC at [cdc.gov/coronavirus/2019-nCoV/index.html](https://www.cdc.gov/coronavirus/2019-nCoV/index.html).



To share feedback on the framework or to submit a resource for this project, visit [TakeCare.Community](https://www.TakeCare.Community).



If you would like more information about the work we are doing, you can sign up for the Take Care Community e-newsletter at [TakeCare.Community/email-updates/](https://www.TakeCare.Community/email-updates/).

Research

University of Pittsburgh. (2020, July). Effects of Covid-19 on family caregivers: A community survey from the University of Pittsburgh.

Read the report: http://www.caregiving.pitt.edu/wp-content/uploads/2020/07/Full_Report_Final.pdf.

Rosalynn Carter Institute for Caregiving. (2020, October). Caregivers in crisis: Caregiving in the time of COVID-19.

Read the report: <https://www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-Report-October-2020-10-22-20.pdf>.

NORC at the University of Chicago. (2021, January). Needs assessment and environmental scan report: Maintaining physical and mental well-being of older adults and their caregivers during public health emergencies.

Read the report: <https://www.norc.org/PDFs/Maintaining%20Physical%20and%20Mental%20Well/ESandNAREportNarrative.pdf>.

Embracing Carers, and initiative of EMD Serono. (2020). The U.S. carer well-being index: Who cares for caregivers? Perspectives on Covid-19 pressures and lack of support.

Read the report: https://www.embracingcarers.com/content/dam/web/healthcare/corporate/embracing-carers/home/document/United_States_Carer_Well-Being_Index_Report_FINAL_11.17.20.pdf.

Acknowledgements

This framework was created through the insights and expertise of caregiving advocates, researchers, innovators, and individual family caregivers, and molded to demonstrate NAC's core values: "Our work is guided by an authentic and passionate commitment to family caregivers that is human-centered, data-driven, collaborative, and inclusive."

The National Alliance for Caregiving and Adira Foundation would like to thank participants of the following meetings for their input:

- National Alliance for Caregiving Board of Directors meeting;
- NAC Research Collaborative meeting;
- NAC Advocacy Collaborative meeting;
- NAC Innovation Collaborative meeting;
- National Community Town Hall (November 2020);
- Global Town Hall on Caregiving and COVID-19 (December 2020).

The framework is open for Public Comment, March - April 2021 at www.TakeCare.Community/the-framework.

Leadership

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About NAC

Established in 1996, the National Alliance for Caregiving envisions a society that values, supports, and empowers family caregivers to thrive at home, work, and life. NAC's mission is to build partnerships in research, advocacy, and innovation to make life better for family caregivers. Working in coalition with national and international organizations and advocates, NAC provides thought-leadership, builds strategic alliances, and convenes stakeholders and advocates. Learn more about our work at www.caregiving.org. Follow on [Facebook](#), [Twitter](#), and [LinkedIn](#).

About The Adira Foundation

Adira is a national, nonprofit foundation whose mission is to invest in better lives for people with neurodegenerative diseases. We work in a cycle of listening, learning and acting to improve with each round of funding. Learn more at www.adirafoundation.org. Follow on [Facebook](#), [Twitter](#), and [LinkedIn](#).