

SUPPORT FAMILY CAREGIVERS

The ongoing COVID-19 pandemic has magnified what we've known all along – our institutions are not prepared to support family caregivers.

We write to urge government, community and religious leaders to please remember the challenges facing family caregivers as this public health crisis continues to unfold. Unpaid family caregivers are the backbone of the health care system in the United States, providing as much as 90 percent of all home health care for no pay and at personal risk. Said differently, more than 44 million Americans (including more than 1.3 million caregiving youth) are providing unpaid care for loved ones across generations, including veterans, people with disabilities and battling chronic illness and elderly.

With an estimated 28 percent of caregivers also “sandwiched” between caring for an aging parent or older adult while raising children, millions of Americans face the pressures of staying healthy while often balancing the demands of work and school. It is also not lost on us that many unpaid family caregivers may now be unemployed as result of economic uncertainty created by this pandemic.

COVID-19 will also thrust many into caregiving roles for the first time, while also requiring existing caregivers to adapt how they carry out their caregiving responsibilities.

Understanding the role family caregivers of all ages play and the challenges they face will be key to effectively navigating this pandemic. We hope this understanding leads to support across public and private institutions nationwide.

How COVID-19 Amplifies Caregiving Challenges

Unpaid caregivers provide care in several ways:

- Assisting with daily living tasks (e.g., eating, bathing)
- Managing medications

- Coordinating health care needs and appointments
- Monitoring and managing personal finances
- Providing emotional support

In short, family caregivers provide more than 30 billion hours of care annually. This amounts to more than \$500 billion in opportunity cost each year, primarily in the form of forgone wages.

Caregiving is influenced by many variables such as the age and underlying conditions of the person receiving care, as well as the caregiver's individual circumstances. Some live with those for whom they care, others provide care from a distance. Many also work outside the home or attend school, and many must perform caregiving duties without access to paid leave from work or school. Each of these considerations can pose a variety of challenges for individual caregivers.

However, there are two commonalities:

- First, by nature, caregiving is often dynamic and unpredictable. Many caregivers frequently navigate crisis with their loved ones.
- Second, unpaid caregivers keep their loved ones at home, lessening the burden on outside care facilities.

COVID19 is amplifying the challenges and benefits of caregiving. We need to support caregivers of all ages navigate the unforeseen difficulties created by the pandemic, while recognizing the value in keeping loved ones home and not overburdening emergency rooms and hospitals. We also must think critically of how best to provide respite to family caregivers, especially as outlets needed for a break close (senior centers, hair salons, etc).

In addition to the mounting day-to-day challenges, the COVID19 pandemic amplifies the following:

- School or work closures (including teleworking requirements) can amplify and complicate care responsibilities, particularly for sandwich generation caregivers and caregiving youth

- Home health aides, already insufficient, may become unavailable, particularly as the pandemic both increases care needs and reduces availability of direct care workers and volunteers
- Long-distance caregivers may not be able to travel to loved ones
- Caregivers may not be able to visit, monitor or coordinate care for loved ones living in facilities closed to access
- Fewer people may be available to provide care as primary caregivers get sick from COVID-19 or other health issues
- Access to necessities including prescription medications and food may become difficult or limited
- Access to care

How to Support Caregivers During the COVID-19 Emergency

Research shows that family caregivers face increased risk for health, emotional, financial, and work-related problems. The following options, however, can help new and existing caregivers adapt:

- Using telehealth options to connect with health care providers (for both caregivers and care recipients)
- Using mail order to fill prescriptions and deliver medical supplies
- Arranging grocery/pharmacy delivery
- Connecting with online or telephone support groups
- Creating closed groups on social media to stay in contact with fellow caregivers and/or members of support team

On an informal level, support caregivers you know by:

- Checking in on your friends/relatives/neighbors who are caregivers and encourage them reach out

- Asking if they need help and if they are ok
- Volunteering to get groceries and supplies for those who are too vulnerable to shop
- Observing social distancing to stop community spread

Sincerely, United Together:

American Association of Caregiving Youth-
ARCH National Respite Network and Resource Center-
Caregiver Action Network-
Caring Across Generations-
Elizabeth Dole Foundation-
Family Caregiver Alliance-
National Alliance for Caregiving-
Rosalynn Carter Institute for Caregiving

STAY INFORMED WITH THE FOLLOWING RESOURCES

Public Health Resources

Centers for Disease Control (CDC) >

World Health Organization (WHO) >

Other Government Resources:

Department of Labor (DOL) >

Department of Energy (DOE) >

National Institutes of Health (NIH) >

Administration for Community Living (ACL) >

USA.gov >

Local Health Department

Caregiver Support Services and Communities

[ARCH National Respite Locator Service >](#)

[Caring Across Generations and National Alliance for Caregiving:
Tips for Sandwich Generations Caregivers In the Era of COVID-19 >](#)

[Caregiver Action Network, Caregiver Help Desk >](#)

[Family Caregiver Alliance >](#)

[Aggregated COVID-19 information & national webinars on coping with caregiving during the COVID-19 Crisis;](#)

[800.445-8106 national calls; 415.434.3388 San Francisco Bay Area services](#)

[Hidden Heroes Caregiver Community >](#)

[An online platform for military and veteran caregivers hosted by the Elizabeth Dole Foundation](#)

[Rosalynn Carter Institute:](#)

[Virtual coaching for veteran caregivers >](#)

[Virtual coaching for dementia caregivers >](#)

[Caring During COVID-19 >](#)

[National Association of Area Agencies on Aging \(N4A\) – Eldercare Locator >](#)

[Resources for Specific Caregiving Populations, including:](#)

[Alzheimer’s Association/Alzheimer’s Foundation of America >](#)

[American Association of Caregiving Youth \(AACY\) >](#)

[American Cancer Society/Cancer Support Community >](#)

[Mental Health America/National Alliance on Mental Illness](#)

[\(NAMI\) >](#)