Center to
Advance
Palliative Care
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The Case

for Caregiver Support

Better Outcomes for People
and Organizations

> “For those who have been thrust into the role, caregiving can be an extremely lonely, stressful, and frustrating responsibility. We need to recognize and appreciate the contributions of our caregivers and give them all the support we can in their homes and communities.”
>
> **Rosalynn Carter, Former First Lady**

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Suggested Citation: Heitner R, Silvers A, Bowman B, Applebaum A. *The Case for Caregiver Support: Better Outcomes for People and Organizations,* Center to Advance Palliative Care, 2026.

Developed with generous support from Robert W. Gottesman and Trudy Elbaum Gottesman.

Meet Diana

Diana is a 52-year-old woman with a husband, two college-aged children, and a dog. Her mother, Esther, has Alzheimer's disease and moved in with Diana and her family two months ago when she began to need more support than her assisted living facility could provide. Since Esther moved in, Diana has had to switch from working full-time to part-time to care for her mother.

Her daughter, Sophie, is competing in a swim meet next week, but Diana will miss it because she needs to stay home with Esther. A few nights ago, Esther tried to leave the house, but luckily the noise she made woke everyone up. Now, Diana and her husband take turns sitting next to Esther's bed while she sleeps.

Last night, Diana started experiencing chest pains and was taken to the emergency department (ED). She was diagnosed with a panic attack and was told to try to reduce the amount of stress in her life—but she doesn't know how anything can change when she has so many competing priorities.

We need to do better to support Diana.

A Pressing Call to Action: The Consequences of Caregiver Burden

There are 63 million people in the U.S. who serve as caregivers—family, friends, or anyone who provides care to individuals living with chronic or serious illnesses, disabilities, or mental health challenges.[1]

Approximately one in four adults in the U.S. identifies as a caregiver, a 32% proportional increase over the last decade alone (18.2% vs. 24.0%).[2]

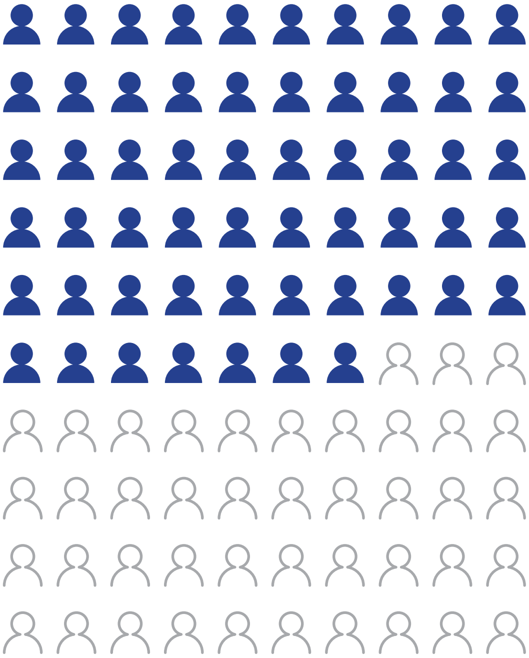
Two-thirds of caregivers help with activities of daily living, such as toileting and feeding, and 55% perform medical and nursing tasks. These responsibilities often persist over time, averaging more than 5.5 years.[1]

Many caregivers face psychological and social challenges from this role. Caregivers report high emotional and physical strain, social isolation, financial and employment difficulties, and other negative consequences.[1] Nearly one-quarter of caregivers report difficulty caring for their own health and are more likely to experience physical decline and new illnesses themselves.[1,3,4]

High-Intensity Caregiving in the U.S.[1]

57%

of caregivers report high-intensity caregiving situations



Caregivers also often suffer from mental health challenges, including:

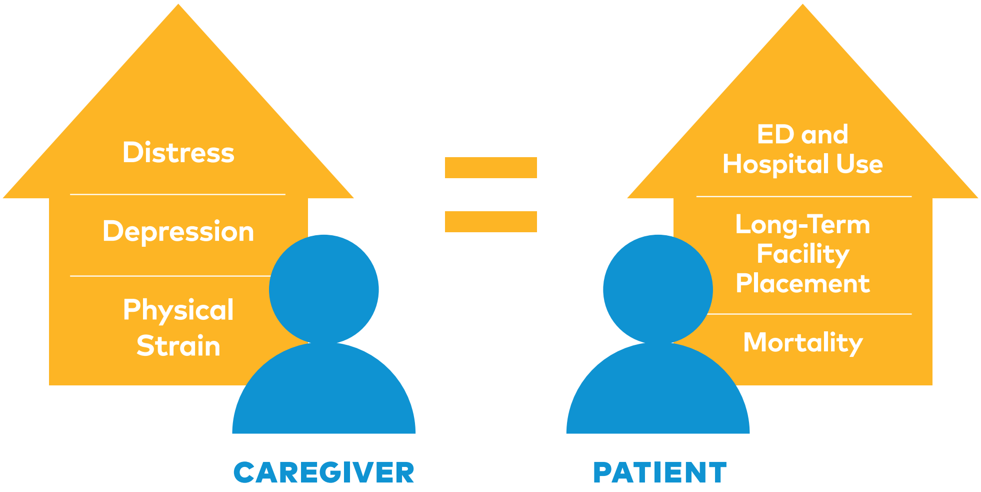
- → **Anxiety**[5,6]
- → **Depression**[6,7]
- → **Sleep difficulties**[8]
- → **Post-traumatic stress symptoms**[9,10]

The bottom line: the physical, psychological, and social impact of caregiving takes a toll—and is associated with 29% higher health care spending for those who are caregivers.[11]

Caregiver Distress Drives Poor Outcomes and Increased Health Care Spending for Patients

Not only does caregiving have a direct impact on the health and health spending of caregivers, but patient or care recipient (hereafter referred to as patient) health status and spending are also tied directly to their caregivers' well-being.

The Impact of Caregiver Burden on Patient Outcomes[12-20]



Ankuda et al. found that various aspects of caregiver distress, such as depressive symptoms, sadness, and fatigue, were significantly associated with patients' Medicare expenditures and utilization.[12] Studies have also shown that high caregiver stress, depression, or burden leads to increases in ED visits, hospitalizations, and long-term nursing home stays.[13-17] Caregiver mental health or burden has also been found to be associated with higher patient mortality.[18-20]

What can we learn from this? Providing better support to caregivers is essential for the patients and families we serve—and to the bottom lines of health care organizations and payers.

Caregiver Support Programs Make a Difference in Outcomes and Spending

Health care organizations that offer caregiver support programs can proactively identify caregivers in need of additional support and intervene before caregiving stressors lead to unnecessary suffering and health care utilization. In particular, programs that offer professional mental health services and psychosocial support have been shown to improve caregiver quality of life, as well as both caregiver and patient health care utilization and costs. For example:

- → Telephonic psychosocial support for caregivers can reduce caregiver ED visits and hospitalizations.[21]
- → Effective care management for dementia caregivers improves patient quality of life and reduces ED utilization.[22]
- → Caregiver psychosocial coaching improves self-efficacy, with a resultant decrease in the odds of patient hospitalization.[23]
- → Interventions that target caregivers' capacity to manage anxiety also help caregivers manage uncertainty and the day-to-day challenges of caregiving.[24,25]
- → Brief communication skills training for caregivers improves their capacity to engage in advance care planning discussions; it also leads to reductions in distress and anxiety, and to improvements in preparedness for patient death.[26]

OUTCOME SPOTLIGHT

Resources for Enhancing All Caregivers' Health (REACH VA)[27]

This structured caregiver support program provides caregivers of Veterans Affairs (VA) patients with a limited number of sessions with a certified coach. Not only does this program decrease caregiver burden and depression, but financial analysis confirms that it holds health care spending stable for caregivers, and patient VA costs are **33.6% lower** for a matched comparison group.

Effective Caregiver Support: Peter's Story

Peter was present for every phase of his husband's journey with glioblastoma, from initial symptoms to diagnosis, surgeries, treatment, and follow-up. He attended all appointments, tracked symptoms, administered medications, researched treatment options, managed finances and paperwork, and provided constant emotional support—all while maintaining full-time employment to preserve their health insurance coverage.

Peter's distress deepened when a second brain tumor emerged after multiple rounds of surgery, chemotherapy, and radiation. At that point, his husband's oncologist referred him to the Caregivers Clinic at Memorial Sloan Kettering Cancer Center, where he received seven sessions of Meaning-Centered Psychotherapy for Cancer Caregivers.

Before Engaging in Caregiver Support Services

- Peter and his husband had differing understandings of the illness trajectory, leading to misaligned expectations for the future.
- Peter's emotional exhaustion made it difficult to balance caregiving and other aspects of his life.
- He tried traditional mental health therapy, but without the therapist's understanding of his husband's cancer journey, the sessions often felt unproductive. Too much time was spent updating the therapist on his husband's care, leaving little time for deeper emotional processing.

After Engaging in Caregiver Support Services

- Improved communication between Peter and his husband enabled joint planning for the future and emotional alignment.
- Improved coping skills allowed Peter to maintain his job during a high-stress period.
- Smoother care transitions ensued, as emotional preparedness made it easier to handle practical demands. Peter experienced a greater sense of meaning and purpose in caregiving and life more generally, despite his husband's decline and ultimate death.
- A clearer path forward after his husband's death accelerated Peter's reintegration into daily life and society.

Caregiver Support Programs: Feasible, Budget-Neutral, and Beneficial for Health Care Organizations

Not only do health care organization-based caregiver support programs have a positive impact on both caregivers and the patients they care for, but these programs also produce solid financial results.

A formal caregiver support program establishes the caregiver as a patient of the organization—importantly, with their own independent medical record—and thus creates an ethical and compliant mechanism to bill for services delivered to the caregiver.[28] As a result, much-needed support services provided to caregivers, including evaluations, psychotherapy visits, and potential medication management visits, are all revenue-generating.

Annual net revenue will depend on the staffing model, the payer mix, negotiated payment rates, and the mix of services needed by the caregivers served. Using national medians, a caregiver support program is calculated to generate a small positive net income on an annual basis. Further, using national productivity standards, a caregiver support program could fully cover its costs at 85-90% of total annual capacity.[29]

In other words, caregiver support programs can be financially self-sustaining.

Because a caregiver support program can cover its operational expenses, and presents no need for capital investment, the many additional business benefits of the program are achieved at no cost to the organization.

Some of these business and financial benefits may include:

- → **Positive public relations.** Caring for caregivers makes inherent sense to a public where one in every four adults is a caregiver.[1] Major health care organizations have launched advertising campaigns to highlight their resources specifically for family caregivers.

  Example Advertisement

WE TREAT
PEOPLE WITHOUT
CANCER, TOO.

It's a helpless feeling to find out someone you love has cancer. Friends and family are often hit just as hard as the person diagnosed. That's why we offer caregiver support services to help people deal with this difficult situation while knowing their loved one is being taken care of. At Memorial Sloan Kettering, we're here for everyone affected by cancer — whether they're our patient, or a caregiver.
Learn more at MSKCC.ORG/MORESCIENCE

MORE
SCIENCE.
LESS
FEAR.

1884

Memorial Sloan Kettering
Cancer Center

MANHATTAN · BROOKLYN · LONG ISLAND · WESTCHESTER COUNTY · BASKING RIDGE, NJ
In-network with most health plans. Ask about financial assistance.

- → **Improved opportunities for financial bonuses.** Reduced caregiver distress improves the cost-effectiveness of care for the patient. For organizations participating in shared savings and other value-based payment models, the caregiver support program could contribute to utilization reductions that result in financial bonuses and shared savings.
- → **New opportunities for philanthropy.** Tangible improvements in caregiver mental health create a pipeline of grateful patients and widen the circle of individuals positively impacted by the health care organization.

Caregiver support programs advance both mission and margin, making this a prime strategic opportunity for health care organizations.

Resources for Establishing a Caregiver Support Program

A number of leading health care organizations have launched their own caregiver support programs, and best practices are emerging. The following guidance and resources may be useful for caregiver support program champions, as they work to match their efforts with community needs and secure leadership support:

Implementation Resources

- → **American Cancer Society Developing Caregiver Clinical Services Toolkit**
- → **Center to Advance Palliative Care (CAPC) Caregiver Support Program Implementation Toolkit**

Program Examples

- → **Steven S. Elbaum Family Center for Caregiving at Mount Sinai**
- → **RUSH Caring for Caregivers (C4C)**
- → **University of Alabama at Birmingham Health System: Caregiver & Bereavement Support**
- → **U.S. Department of Veterans Affairs: VA Caregiver Support Program**

> "There are real, affordable interventions that can help caregivers and lead to real social and economic benefits. The sooner caregivers are able to re-emerge and re-engage with the labor market and re-engage with their communities, the better. These are exactly the kinds of programs that the U.S. should be investing in."

Peter, Caregiver

> "Health care systems often fail to recognize family caregivers as formal members of the care team, and support services rarely address caregivers' individual needs across different care settings. Only 29% of [cancer] caregivers report being asked by a health care professional about their caregiving needs; this rate drops to 13% when the question referred to what the caregiver needed to be able to care for themselves."[30]

National Alliance for Caregiving

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About the Center to Advance Palliative Care capc.org

The **Center to Advance Palliative Care (CAPC)** is a national organization dedicated to increasing the availability of quality, equitable health care for people living with a serious illness. As the nation's leading resource in its field, CAPC provides health care professionals and organizations with the training, tools, and technical assistance necessary to effectively meet this need. CAPC is part of the Icahn School of Medicine at Mount Sinai, in New York City.

> "Caregivers are the backbone of our health care system, but without support, they will be unable to fulfill their critical role on the health care team."

Allison Applebaum, PhD, FAPOS
Director, Steven S. Elbaum Family Center for Caregiving

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