

## ISSUE BRIEF: Supporting Informal Caregivers of Your Older Adult Patients

This issue brief provides information for health care providers to support caregivers on how to recognize and access social enabling services for their older adult family members.

*“Almost 18 million Americans provide care for a chronically ill, disabled, or aged family member or friend during any given year. Almost two-thirds of people age 65 and older rely exclusively on informal care for their personal care needs. An additional 30 percent use a mix of paid and unpaid care.”<sup>1</sup>*



Social factors play a critical role in their mental health, physical health, and overall quality of life, as they rely on family, friends, or organizations to assist them with daily activities, provide companionship, and care for their well-being.<sup>2</sup> Social factors are at the root of health inequalities and

social determinants can account for up to 40% of individual health outcomes.<sup>3</sup> It is therefore important that policymakers, advocates, primary care providers, and caregivers have a stake in supporting and implementing programs and policies that can help older adults live in and engage with their communities.

### What Denotes an Individual as a Caregiver?

- ✎ A caregiver can be either formal (paid/volunteer) or informal (family). We will refer to the informal (family) caregiver in this brief.
- ✎ A family caregiver is defined as any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care.<sup>4</sup>
- ✎ As Americans continue to live longer and the population of older adults' increases, a large number will need to depend on immediate and extended family and friends for some form of care delivery.
- ✎ Caregivers are sometimes considered “secondary patients,” as more than half of caregivers provide over 8 hours of care per week to their loved ones, while 1 in 5 provides over 40 hours a week. They will spend substantially more time providing care than other professional or paid caregivers combined.<sup>5</sup>

Informal family or unpaid caregivers, such as spouses, family, friends and neighbors who care for older adults play a vital role in maintaining their older adult's health, well-being, and quality of life.<sup>6</sup> Therefore, they need to be better integrated into the health care team, and be trained adequately by formal care providers on the knowledge and skills that are required to properly provide the care without compromising the integrity of the older individual and to achieve overall better health outcomes. In addition to knowledge and skills, caregivers need strategies on how to alleviate the stress they may feel from the increasing responsibility of providing this care. Some of the complex tasks caregivers provide include managing multiple medications, providing wound care, managing special diets, giving injections, and operating monitors or other specialized medical equipment, especially after a hospital discharge.

Caregiving is a labor of love and many caregivers work outside their home, which can create conflict between their competing responsibilities, leading to intense stress, absenteeism, workday interruptions, and even potentially poor health outcomes for them as well. As a result, caregivers can face substantial financial and health impacts.<sup>7</sup> Health care professionals should be aware of the hazards caregivers of older adults encounter, such as emotional stress, sleep deprivation, poor nutrition, anxiety, financial concerns, and less attention to their own health and well-being, and among others. Caregivers may not know when they need community-based services and resources, how to access or utilize them, or even know of their availability. Formal care professionals should talk with caregivers and refer them to local and statewide resources.

The following resources provide information on the changing nature of family caregiving and include a national program to support family caregivers.

🕒 **Changing Nature of Family Caregiving: New Research and Policy Interventions**

<https://www.ncoa.org/wp-content/uploads/DAC-Webinar-Family-Caregiving.pdf>

🕒 **National Family Caregiver Support Program (NFCSP)**

<https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>

## **The Caregiver Advise, Record, Enable (CARE) Act**

Health center providers can support their patients' caregivers by referring them to the Caregiver Advise, Record, Enable (CARE) Act. According to the AARP, the CARE Act is a model legislation and tool to enable family and friend caregivers to provide safe and effective home care to older adults. In particular, it supports family caregivers when their loved ones are admitted to the hospital, and helps them learn how to safely provide care at home once their loved ones are discharged.<sup>8</sup>

The CARE Act was enacted in May 2015, and is currently law in 39 states, as well as in the District of Columbia, Puerto Rico, and U.S Virgin Islands.<sup>8</sup> Some of the finer points of the CARE Act include:

- 🕒 The name of the family caregiver is recorded when a loved one is admitted into a hospital or rehabilitation facility.
- 🕒 The family caregiver is notified if the loved one is discharged to another facility or back home.
- 🕒 The hospital or rehabilitation facility must provide an explanation and live instruction of medical tasks, such as medication management, injections, wound care, and transfers that the family caregiver will perform at home.

By sharing essential information and resources like the CARE Act, health center providers can equip caregivers with the knowledge to be advocates for their family members' care during and after a hospital stay.

## **Resources for Family or Informal Caregivers**

There are a growing number of national, state and local organizations providing resources, training, funding, and counseling for informal caregivers. Federal government agencies and non-profit organizations include the [National Institute for Aging](#), [Administration for Community Living](#), and other national organizations such as the [National Council on Aging](#) and the [Family Caregiver Alliance](#). Every state has a number of agencies and programs to assist caregivers in finding what is available in their state and local community. These programs have information easily accessible in multiple languages, and posted around the health center (waiting area, doctor's office). It is important for caregivers to be advocates not only for their older adult family member or friend, but also for themselves and their own well-being. Health center providers can refer their patients' caregivers to the following resources:

### **Make Yourself a Priority, Too: Tips for Caregivers**

<https://www.nia.nih.gov/health/infographics/make-yourself-priority-too-tips-caregivers>

### **Taking Care of Yourself: Tips for Caregivers**

<https://www.nia.nih.gov/health/taking-care-yourself-tips-caregivers>

### **Face the Facts: Topics to Discuss with Aging Parents**

[https://eldercare.acl.gov/Public/Resources/Factsheets/Face\\_the\\_Facts.aspx](https://eldercare.acl.gov/Public/Resources/Factsheets/Face_the_Facts.aspx)

### **Working Caregivers Finding a Balance**

[https://acl.gov/sites/default/files/news%202017-03/Working\\_Caregivers\\_Finding\\_a\\_Balance\\_1.pdf](https://acl.gov/sites/default/files/news%202017-03/Working_Caregivers_Finding_a_Balance_1.pdf)

While some services such as respite care for caregivers may not be covered by insurance, Medicare will cover most of the cost of up to five days in a row of respite care in a hospital or skilled nursing facility for a person receiving hospice care. Medicaid also may offer assistance. Some respite care resources can be found at the [National Respite Locator Service](#), [Eldercare Locator](#), and [Well Spouse Association](#) (solely dedicated to support of spousal caregivers at any age).

## **Conclusion**

As family or informal caregivers often experience burnout and significant health impacts, it is paramount that they are equipped with resources to care for both themselves and their loved ones. Health care providers and case managers can play a vital role in supporting their patients' caregivers.

To better integrate caregivers into the health care team, formal care providers can provide clear health summaries and instructions, information on community-based services and strategies for stress alleviation, and referrals to local and statewide resources. There are an increasing number of nonprofit organizations and government agencies providing tools to help caregivers maintain health and balance so they can advocate for their older adult family members and themselves.

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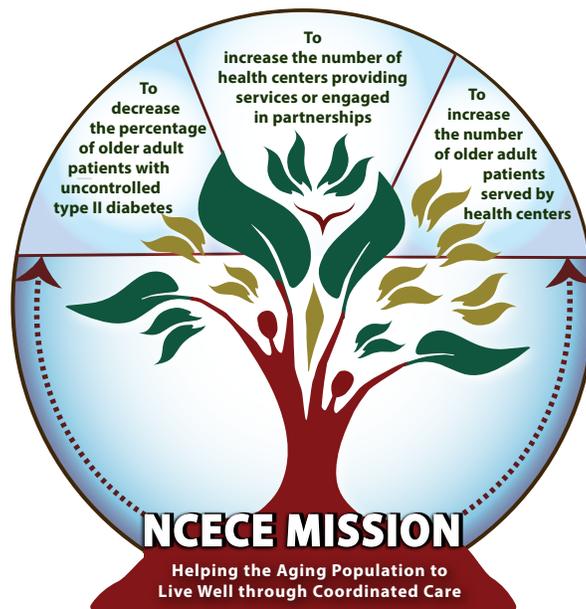
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## References

1. White House Conference on Aging. White House conference on aging final report. Retrieved from <https://whitehouseconferenceonaging.gov/2015-whcoa-final-report.pdf>
2. Centers for Disease Control and Prevention (CDC) Morbidity and Mortality Weekly Report. (2005). Retrieved from <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5417a4.htm>
3. Magnan S. (2017) Social Determinants of Health 101 for Health Care. National Academy of Medicine. Retrieved from <https://nam.edu/social-determinants-of-health-101-for-health-care-five-plus-five/>
4. Family Caregiver Alliance. Definitions.(2017). Social determinants of health 101 for health care. Retrieved from <https://www.caregiver.org/definitions-0>
5. Clancy CM, Lavizzo-Mourey R. Foreword. In: Hughes RG, editor. Patient Safety and Quality: An Evidence-Based Handbook for Nurses. Rockville (MD): Agency for Healthcare Research and Quality (US); 2008 Apr.
6. Williams, A. P., Peckham, A., Kuluski, K., Lum, J., Warrick, N., Spalding, K. . . Im., J. (2015) Caring for Caregivers: Challenging the Assumptions. Healthcare Papers, 15(1), 8–21A.
7. Embracing Carers. (2017). Embracing the critical role of caregivers around the world white paper and action plan. Retrieved from [https://www.embracingcarers.com/content/dam/web/healthcare/corporate/embracing-carers/media/infographics/us/Merck%20GaA%20Embracing%20Carers\\_White%20Paper%20Flattened.pdf](https://www.embracingcarers.com/content/dam/web/healthcare/corporate/embracing-carers/media/infographics/us/Merck%20GaA%20Embracing%20Carers_White%20Paper%20Flattened.pdf)
8. AARP. (n.d.). New state law to help family caregivers. Retrieved from <https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html>