



# Caring for the caregiver: A guide for physicians

A caregiver can be any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for a child 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>1</sup> In the United States, approximately 43.5 million people serve as informal caregivers providing unpaid care to an adult or child.<sup>2</sup> Many of these individuals are full-time caregivers, with one in four providing 41 or more hours per week of in-home care, and the remainder spending an average of 24.4 hours per week providing care.<sup>3</sup>

Caregivers provide a range of duties; the majority of caregivers provide high- or medium-level care involving activities of daily living and/or instrumental activities of daily living situations, such as bathing or performing household chores. Approximately 57 percent of caregivers assist with medical or nursing tasks, such as injections, tube feedings, and catheter and colostomy care.<sup>3</sup> These types of care for a loved one can be meaningful and rewarding, but can also be a source of stress and anxiety. Over 60 percent of caregivers are women<sup>3</sup>, and those who take on the role of caregiver tend to be mothers, daughters and sisters. Potentially exacerbating the risk of caregiver burnout for women is the fact that they can experience anxiety and depression at higher rates than men.<sup>4</sup> In addition to the emotional challenges of caregiving, many also experience physical and financial burdens. Roughly half of caregivers report moderate to high physical strain, and 38 percent report high to moderate financial difficulties as a result of caregiving.

The American Medical Association recognizes that the role of caregiver is one of compassion and immense responsibility. The AMA also acknowledges the mental, physical and financial tolls of caregiving that place an individual at higher risk for experiencing caregiver burnout. The AMA encourages physicians to understand the challenges of informal caregiving and the impact that caregiver burnout can have on patient care. This guide provides an overview of the caregiver role, the factors that contribute to caregiver burnout and helpful resources for you, your patients and their caregivers—or your patients who care for others.

## What causes caregiver burnout?

Caregiver burnout is defined as a state of physical, emotional and/or mental exhaustion that can create negative and unconcerned caregiver attitudes. Caregiver burnout can occur when caregivers don't get the help or support they need, and when the demands on a caregiver's mind, body and emotions are overwhelming, leading to fatigue and sometimes hopelessness.<sup>5</sup> Serving as a caregiver for a loved one is often mentally and physically demanding, making it difficult for the one providing care to tend to their own needs. Once the individual begins to feel the effects of burnout, it becomes difficult to care for themselves, as well as the patient in their charge.

Some common causes of caregiver burnout include:<sup>5</sup>

- **Role confusion:** Many people are confused when thrust into the role of caregiver. It can be difficult for a person to separate her role as caregiver from her role as spouse, lover, child, friend, etc.
- **Unrealistic expectations:** Many caregivers expect their involvement to have a positive effect on the health and happiness of the patient. This may be unrealistic for patients suffering from a progressive disease, such as Parkinson's or Alzheimer's.
- **Lack of control:** Many caregivers become frustrated by a lack of money, resources and skills to effectively plan, manage and organize their loved one's care.
- **Unreasonable demands:** Some caregivers place unreasonable burdens upon themselves, in part because they see providing care as their exclusive responsibility.
- **Other factors:** Many caregivers cannot recognize when they are suffering burnout and eventually get to the point where they cannot function effectively. They may even become sick themselves.

## **What are the symptoms and effects of caregiver burnout?**

Caregiver burnout can create symptoms of stress and depression in the caregiver and negatively affect both the caregiver and the care recipient. Some symptoms manifest externally and are easy to identify, but others are often internal and not as apparent.

If left unaddressed, burnout can have harmful effects for both the caregiver and the patient under their care. Almost 25 percent of caregivers providing more than 40 hours of care per week report their own health has deteriorated as a result of providing care, and more than half of surveyed caregivers report their health decline has affected their ability to provide care.<sup>7</sup> When a caregiver ignores his or her own needs and experiences burnout, he or she can become less empathetic, impatient and even argumentative with the person under their care. If the feelings of burnout lead to more serious levels of anxiety and depression—often highlighted by an increase in alcohol or stimulant use—the caregiver could be mentally and physically impaired, causing risk to the patient. In addition, symptoms of burnout such as depression, anxiety and exhaustion often result in a lowered immune system, putting the patient at risk for additional illness and adverse health outcomes.

### **Common signs of caregiver burnout:<sup>6</sup>**

1. Feeling overwhelmed or constantly worried
2. Feeling tired often
3. Getting too much sleep or not enough sleep
4. Gaining or losing weight
5. Becoming easily irritated or angry
6. Losing interest in activities you used to enjoy
7. Feeling sad
8. Having frequent headaches, bodily pain or other physical problems
9. Abusing alcohol or drugs, including prescription medications



## **How can you help reduce caregiver burnout?**

The AMA recognizes and supports the key role that lay caregivers have in performing health care tasks for loved ones. While the sense of responsibility to care for a loved one is an important part of providing care, compassion fatigue or burnout can result from continued caregiving without emotional support or relief. Physicians, as the primary source of patient care, have an important role in supporting and guiding caregivers.

Physicians can try to mitigate potential stress, burnout or harmful behavior for caregivers by encouraging them to take breaks, maintain a healthy diet, seek preventive health care and join support groups.<sup>7</sup> Physicians can also conduct a systematic assessment to identify needs, strengths and resources for the family caregivers.<sup>8</sup> The Family Caregiver Alliance published a set of guiding principles on effective caregiver assessment, which can assist physicians in creating and maximizing this type of tool.<sup>9</sup>

Research exhibits the potential negative effects of caregiver burden and burnout. The numerous resources outlined here and available from other sources can help mitigate those risks and enable better outcomes for both the patient and the caregiver.



## Where can you find more information?

The following links and resources can help physicians further understand the causes and impacts of burnout on caregivers, and better prepare physicians to support and guide lay caregivers. This is not an exhaustive list, so you are encouraged to further explore other sources of information as needed.

### General resources:

[American Association of Retired Persons \(AARP\) Home and Family Caregiving Guide](#)

[AARP 10 Ways to Deal with Caregiver Stress](#)

[Cleveland Clinic Caregiving: Recognizing Burnout](#)

[Caring.com Caregiving Resources](#)

[Caring.com Caregiver Burnout Assessment](#)

[Amyotrophic Lateral Sclerosis Association \(ALSA\) Symptoms of Caregiver Burnout](#)

[National Hospice & Palliative Care Organization Caregiving Guide](#)

[National Alliance for Caregiving](#)

### Resources by medical condition:

#### Cancer

[American Cancer Society Caregivers and Family](#)

Gilda's Club chapters—look for local chapter support groups for caregivers of cancer patients

#### Cardiovascular/heart diseases

[American Heart Association Resources for Caregivers](#)

[Answers by Heart Fact Sheet: Lifestyle and Risk Reduction—what is caregiver burnout?](#)

#### Neurological diseases

[Alzheimer's Association Alzheimer's and Dementia Caregiver Center](#)

[Amyotrophic Lateral Sclerosis Association Caregiver Resources](#)

#### Child and adult disabilities

[Easterseals Resources for Caregivers](#)

## References

1. Family Caregiver Alliance National Center on Caregiving. Definitions. 2014; Available from: [www.caregiver.org/definitions-0](http://www.caregiver.org/definitions-0). Accessed March 15, 2018.
2. Family Caregiver Alliance National Center on Caregiving. Caregiver Statistics: Demographics. 2016: San Francisco.
3. AARP Public Policy Institute and National Alliance for Caregiving. Caregiving in the U.S. 2015 Research Report. 2015.
4. Anxiety and Depression Association of America. Girls and Women, Understanding the Facts: Depression; Available from: [adaa.org/understanding-anxiety/depression](http://adaa.org/understanding-anxiety/depression). Accessed March 15, 2018.
5. Cleveland Clinic. Caregiving: Recognizing Burnout. 2012; Available from: [my.clevelandclinic.org/health/diseases/9225-caregiving-recognizing-burnout](http://my.clevelandclinic.org/health/diseases/9225-caregiving-recognizing-burnout). Accessed on March 15, 2018.
6. Mayo Clinic. Caregiver stress: Tips for taking care of yourself. 2018; Available from: [mayoclinic.org/healthy-lifestyle/stress-management/in-depth/caregiver-stress/art-20044784](http://mayoclinic.org/healthy-lifestyle/stress-management/in-depth/caregiver-stress/art-20044784). Accessed March 15, 2018.
7. National Alliance for Caregiving and Evercare. Study of Caregivers in Decline: Findings from a National Survey. 2006; Minnetonka, Minn.
8. Collins, L.G. and K. Swartz. Caregiver care. *Am Fam Physician*, 2011. 83(11): p. 1309-17.
9. Family Caregiver Alliance. Caregiver Assessment: Principles, Guidelines and Strategies for Change, Report from a National Consensus Development Conference. 2006: San Francisco.