



## *A Time to Take Action*

Caregivers deserve recognition and support

**A**LTHOUGH THE TOPIC IS prominent enough to gain national recognition, there are many who do not understand the critical role that informal caregivers play in our society. Informal caregiving, also called unpaid or family caregiving, accounts for about 80 percent of all long-term care services in the U.S.

The monetary value of services provided for “free” by informal caregivers has been recently estimated at about \$350 billion. This amount is comparable with the total spending of the Medicare program, which was estimated at \$342 billion in 2005, and is about twice as much as spending for homecare and nursing home services combined.

Unpaid caregivers are the foundation of the long-term health care system in the United States; we do not have the resources that would be necessary to replace these caregivers with paid medical professionals. Although we currently have some legislation in place that was

designed to protect this informal institution, additional public policy is needed to grant some relief to those providing care.

For the past 12 years, the month of November has been nationally recognized as National Family Caregivers (NFC) Month to celebrate informal caregivers and recognize the personal sacrifices they often make to ensure a

family member or newborn. Several years later in 2000, the National Family Caregiver Support Program (as part of amendments to the Older Americans Act) was created to offer support services to family members providing care for individuals with disabilities and grandparents caring for grandchildren. Most recently, in 2006, the Lifespan Respite

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better life for someone else. Additionally, NFC Month highlights the importance of supporting, educating, and empowering caregivers, and the need to develop policies to protect and sustain informal caregiving.

The Family and Medical Leave Act (FMLA) of 1993, the first national policy of its kind, gave informal caregivers some aid by allowing employees to take 12 weeks of unpaid leave to care for an ill

Care Act was signed into law. This allows \$289 million over five years for state grants to develop lifespan respite programs that aid families in accessing quality, affordable respite care.

Taking into account that nearly 65 percent of informal caregivers have been employed while providing care and the average length of caregiving is 4.3 years, it is clear that such policies are essential to sustaining informal caregiving.

Caregiving is not an easy task; it even has a direct impact on the health of those providing care. Providing care on any level can be both emotionally and physically draining.

Infectious diseases like colds and flu are more prevalent among caregivers than non-caregivers and chronic diseases

Families with a family member in need of assistance with daily-living activities spend more than twice as much as other families on out-of-pocket medical expenses. These factors, especially in combination with the loss of wages and benefits as a result of time spent away from work, can create a particularly

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and depression are about twice as common. Sleep deprivation is also widespread among caregivers, which can lead to a weakened immune system. The level of stress involved with providing informal care can cause a caregiver to age prematurely, shortening his or her life by as much as ten years. Many times caregivers neglect their own needs in order to care for another.

As much as caregiving responsibilities affect the caregiver's physical and mental well-being, they also have an impact on his or her job. Sixty-two percent of employed family caregivers have had to make some kind of adjustment to their work life as a result of caregiving responsibilities. These adjustments can include anything from coming in late to giving up work entirely.

Many employed informal caregivers eventually go from full-time to part-time jobs as a result of their caregiving responsibilities. While modifying work schedules can help accommodate the responsibilities of providing care, it can also exacerbate the caregiver's economic situation.

Caregiving families, families in which there is one member with a disability, have a 15 percent lower median income than their non-caregiving counterparts.

debilitating financial situation for those caring for a chronically ill or disabled relative or friend.

Caregiving can be a very thankless job. Many caregivers go unnoticed by everyone except for those under their care. Some of the emotional side effects of long-term illness can make a caregiver's task even more challenging.

Depression, often caused by loss of freedom or independence, is a side effect of long-term illness and can result in difficult behaviors on the part of the care recipient. It is extremely common for care recipients to exhibit some type of personality changes caused by the stress of an illness or disability. Care recipients' feelings of frustration, helplessness, or anxiety can create unreasonable or angry behavior making a caregiver's job extremely exhausting.

Even as 50 million Americans act as informal caregivers, it is easy to understand how so many feel isolated and alone. There is much more that can be done, by both policymakers and individuals, to assist them. Providing more effective resources and support for caregivers is not only morally responsible, but also critical to the well-being of the long-term care system and the economy. ♦

### **Where can I go for help?**

If you are an unpaid caregiver, there are many resources available for your use. Take advantage of support groups or respite services in your area. Recruit volunteers from religious groups or civic organizations or ask your family, friends, or neighbors. Anything they can do to save you time will help you provide better care for yourself and your loved one.

#### *Online Resources*

#### **[www.familycaregiving101.org](http://www.familycaregiving101.org)**

Family Caregiving 101 offers tips and strategies on providing care as well as resources to help informal caregivers find assistance.

#### **[www.caregiverslibrary.org](http://www.caregiverslibrary.org)**

The National Caregivers Library is an extensive collection of articles, forms, checklists, and links to topic-specific external resources.

#### **[www.nfcacares.org](http://www.nfcacares.org)**

The National Family Caregivers Association site has a variety of information, links, and resources. Sign up to request the quarterly newsletter, *TAKE CARE!*, written from the perspective of the family caregiver.

#### **[www.caregiver.org](http://www.caregiver.org)**

In addition to its many other resources, the Family Caregiver Alliance website provides a state-by-state guide to help caregivers find assistance and information in their area.

### **What can I do to help?**

If you know a caregiver in need of help, volunteer to cook a meal, run an errand, walk the dog, or mow the lawn. If you don't know anyone personally who needs help, volunteer for a civic association that provides services to informal caregivers. To help advance efforts to create legislation to protect family caregivers, contact your local senator or representative (visit [www.house.gov](http://www.house.gov) or [www.senate.gov](http://www.senate.gov) to find out how.) For more on family caregiving legislation currently before congress, visit the caregiver advocacy section of [www.nfcacares.org](http://www.nfcacares.org).