

## Caregiver Supportive Services

Caregiving refers to attending to another individual's health needs. Caregiving often includes assistance with one or more activities of daily living (ADLs), such as bathing and dressing, as well as multiple instrumental activities of daily living (IADLs), such as paying bills, shopping and transportation. More than 15 million Americans provide unpaid care for people with Alzheimer's disease and other dementias more caregivers, whereas 23 percent of people without dementia rely on three or more unpaid caregivers. Only a small percentage of older adults with dementia do not receive help from family members or other informal care providers (8 percent). Of these individuals, more than 40 percent live alone, perhaps making it more difficult to ask for and receive informal care.

## Caregiver Emotional Well-Being

Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others, they also report high levels of stress when providing care:

- Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial financial, emotional and physical difficulties.
- Fifty-nine percent of family caregivers of people with Alzheimer's and other dementias rated the emotional stress of caregiving as high or very high
- Approximately 40 percent of family caregivers of people with dementia suffer from depression, compared with 5 to 17 percent of non-caregivers of similar ages. Rates of depression increase with the severity of cognitive impairment of the person with dementia.
- One in five (22 percent) caregivers of people with Alzheimer's disease or another dementia has difficulty with medical/nursing tasks, compared with 11 percent of caregivers of individuals without dementia.
- According to the 2014 Alzheimer's Association poll, respondents often believed they had no choice in taking on the role of caregiver.
- The 2014 Alzheimer's Association poll also found that women with children under age 18 felt that caregiving for someone with Alzheimer's disease was more challenging than caring for children (53 percent).
- The demands of caregiving may intensify as people with dementia approach the end of life. In the year before the person's death, 59 percent of caregivers felt they were "on duty" 24 hours a day, and many felt that caregiving during this time was extremely stressful. One study of end-of-life care found that 72 percent of family caregivers experienced relief when the person with Alzheimer's disease or another dementia died.

- Sandwich generation caregivers indicate lower quality of life and diminished health and health behaviors (for example, less likely to choose healthful foods and less likely to exercise) compared with non-sandwich generation caregivers or non-caregivers.

### Caregiver Physical Health

For some caregivers, the demands of caregiving may cause declines in their own health. Evidence suggests that the stress of dementia care provision increases caregivers' susceptibility to disease and health complications. Thirty eight percent of Alzheimer's and dementia caregivers indicate that the physical impact of caregiving was high to very high. Sleep disturbances, which can occur frequently when caring for a relative with Alzheimer's disease or another dementia, have also been shown to negatively influence family caregivers' health. Caregivers of people with Alzheimer's disease and other dementias were also more likely to indicate a high degree of physical strain related to care provision than other caregivers (28 percent versus 17 percent, respectively)

### General Health

Seventy-four percent of caregivers of people with Alzheimer's disease and other dementias reported that they were "somewhat concerned" to "very concerned" about maintaining their own health since becoming a caregiver. Dementia caregivers were more likely than non-caregivers to report that their health was fair or poor. Dementia caregivers were also more likely than caregivers of other older people to say that caregiving made their health worse.

### Physiological Changes

The chronic stress of caregiving is associated with physiological changes that could increase the risk of developing chronic conditions. For example, several studies found that under certain circumstances some Alzheimer's caregivers were more likely to have elevated biomarkers of cardiovascular disease risk and impaired kidney function risk than those who were not caregivers.

Caregivers of a spouse with Alzheimer's or another dementia are more likely than married non-caregivers to have physiological changes that may reflect declining physical health, including high levels of stress hormones, reduced immune function, slow wound healing, increased incidence of hypertension, coronary heart disease and impaired function of the endothelium (the inner lining of blood vessels). Some of these changes may be associated with an increased risk of cardiovascular disease.

### Health Care

The physical and emotional impact of dementia caregiving is estimated to have resulted in \$10.2 billion in health care costs in the United States in 2015.

**CAREGIVER SUPPORTIVE SERVICES RECOMMENDATION:** Introduce caregivers to programs and services which promote their own well being and understanding of Alzheimer’s disease and other related disorders. Empower caregivers with knowledge to assist them to best care for and support people living with Alzheimer’s disease and other related disorders.

Support efforts to promote and fund caregiver supportive services offered by Alzheimer’s Association, Cleveland Clinic Keep Memory Alive and Nevada Senior Services. Services to include but not limited to family care consultation, caregiver support groups, educational programs and services

Support the Dementia Friendly America initiative and its implementation through its key State Champions Group. The Dementia Friendly America initiative is catalyzing a movement to more effectively support and serve those across America who are living with dementia and their family and care partners.

**Caregiver Supportive Service Indicator:** Establishment of a key partners group who will collaborate create and provide a system of referrals to appropriate services. Collaboration with the Aging and Disability Services Division in order to track and analyze data compiled from its provider network and key partners group. In collaboration with ADSD the Dementia Friendly Champions group continually rolls out Dementia Friendly Nevada throughout the state, providing data and recommendations throughout the process.

**Potential Funding:** Older Americans Act funds and other discretionary grants.

<sup>1</sup> Alzheimer’s Association 2015 Alzheimer’s Disease Facts and Figures. Alzheimer’s & Dementia 2015; 11(3)332+ “2015 Alzheimer’s Disease Facts and Figures