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Caregiver Health

A Population at Risk

An estimated 44 million Americans age 18 and older provide unpaid assistance and support to older people and adults with disabilities who live in the community.¹ The value of this unpaid labor force is estimated to be at least \$306 billion annually,² nearly double the combined costs of home health care (\$43 billion) and nursing home care (\$115 billion).³

Evidence shows that most caregivers are ill-prepared for their role and provide care with little or no support,^{4, 5, 6} yet more than one-third of caregivers continue to provide intense care to others while suffering from poor health themselves.⁷ Studies have shown that an influential factor in a caregiver's decision to place an impaired relative in a long-term care facility is the family caregiver's own physical health.^{8, 9, 10, 11}

A substantial body of research shows that family members who provide care to individuals with chronic or disabling conditions are themselves at risk. Emotional, mental, and physical health problems arise from complex caregiving situations and the strains of caring for frail or disabled relatives.

Today, medical advances, shorter hospital stays, limited discharge planning, and expansion of home care technology have placed increased costs as well as increased care responsibilities on families, who are being asked to shoulder greater care burdens for longer periods of time.^{12, 13} To make matters worse, caregivers are more likely to lack health insurance coverage due to time out of the workforce.¹⁴ These burdens and health risks can hinder the caregivers' ability to provide care, lead to higher health care costs and affect the quality of life of both the caregiver and care receivers.

Impact of Caregiving on Caregiver Mental and Emotional Health

The psychological health of the family caregiver is negatively affected by providing care. Higher levels of stress, anxiety, depression and other mental health effects are common among family members who care for an older relative or friend.

Caregivers show higher levels of depression.

- Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among their noncaregiving peers.^{15, 16, 17, 18, 19}
- Estimates show that between 40 to 70% of caregivers have clinically significant symptoms of depression, with approximately one quarter to one half of these caregivers meeting the diagnostic criteria for major depression.²⁰
- Both caregiver depression and perceived burden increase as the care receiver's functional status declines.²¹ Thus, higher levels of clinical depression are attributed to people caring for individuals with dementia. Studies show that 30 to 40% of dementia caregivers suffer from depression and emotional stress.^{22, 23}
- Depression and anxiety disorders found in caregivers persist and can even worsen after the placement of the patient in a nursing home. Many caregivers who institutionalize their relative report depressive symptoms and anxiety to be as high as it was when care

was in the home.²⁴

- Depressed caregivers are more likely to have coexisting anxiety disorders, substance abuse or dependence, and chronic disease. Depression is also one of the most common conditions associated with suicide attempts.²⁵

Caregivers suffer from high levels of stress and frustration.

- Caregivers have higher levels of stress than noncaregivers.²⁶ They also describe feeling frustrated, angry, drained, guilty or helpless as a result of providing care.²⁷
- Some 16% of caregivers feel emotionally strained and 26% say taking care of the care recipient is hard on them emotionally.²⁸ An additional 13% of caregivers feel frustrated with the lack of progress made with the care recipient.²⁹
- Caregiving can also result in feeling a loss of self identity, lower levels of self esteem, constant worry, or feelings of uncertainty.³⁰ Caregivers have less self-acceptance and feel less effective and less in control of their lives than noncaregivers.^{31, 32}
- More than one-fifth (22%) of caregivers are exhausted when they go to bed at night, and many feel they cannot handle all their caregiving responsibilities.³³
- Caregivers who experience chronic stress may be at greater risk for cognitive decline including loss in short-term memory, attention and verbal IQ.^{34, 35, 36}

Health Consequences for Women Caregivers:

- Research shows that female caregivers (who comprise about two-thirds of all unpaid caregivers)^{41,42} fare worse than their male counterparts, reporting higher levels of depressive and anxiety symptoms and lower levels of subjective well-being, life satisfaction, and physical health than male caregivers.^{43,44,45}
- According to one study, there is a dramatic increase in risk of mental health consequences among women who provide 36 or more hours per week of care to a spouse.⁴⁶
- In a national survey on caregiver health, more than one in five (21%) women surveyed had mammograms less often.⁴⁷

Stressful caregiving situations may lead to harmful behaviors.

- As a response to increased stress, caregivers are shown to have increased alcohol and other substance use. Several studies have shown that caregivers use prescription and psychotropic drugs more than noncaregivers.^{37, 38}
- Family caregivers are at greater risk for higher levels of hostility than noncaregivers.³⁹
- Spousal caregivers who are at risk of clinical depression and are caring for a spouse with significant cognitive impairment and/or physical care needs are more likely to engage in harmful behavior toward their loved one.⁴⁰

Impact of Caregiving on Caregiver Physical Health

High rates of depressive symptoms and mental health problems among caregivers, compounded with the physical strain of caring for someone who cannot perform activities of daily living (ADLs), such as bathing, grooming and other personal care activities, put many caregivers at serious risk for poor physical health outcomes. Indeed, the impact of providing care can lead to increased health care needs for the caregiver.

Caregivers are in worse health.

- About one in ten (11%) caregivers report that caregiving has caused their physical health to get worse.⁴⁸
- Caregivers have lower levels of subjective well-being and physical health than noncaregivers.^{49, 50} In 2005, three-fifths of caregivers reported fair or poor health status, one or more chronic conditions, or a disability, compared with one-third of noncaregivers.⁵¹ Caregivers also reported chronic conditions (including heart attack/heart disease, cancer, diabetes and arthritis) at nearly twice the rate of noncaregivers (45 vs. 24%).⁵²
- Caregivers suffer from increased rates of physical ailments (including acid reflux, headaches, and pain/aching),⁵³ increased tendency to develop serious illness,⁵⁴ and have high levels of obesity and bodily pain.⁵⁵
- Studies demonstrate that caregivers have diminished immune response, which leads to frequent infection and increased risk of cancers.^{56, 57, 58} For example, caregivers have a 23% higher level of stress hormones and a 15% lower level of antibody responses.⁵⁹ Caregivers also suffer from slower wound healing.⁶⁰
- The physical stress of caregiving can affect the physical health of the caregiver, especially when providing care for someone who cannot transfer him/herself out of bed, walk or bathe without assistance. Ten percent of primary caregivers report that they are physically strained.⁶¹

Caregivers have an increased risk of heart disease.

- Caregivers exhibit exaggerated cardiovascular responses to stressful conditions which put them at greater risk than noncaregivers for the development of cardiovascular syndromes such as high blood pressure or heart disease.^{62, 63}
- Women providing care to an ill/disabled spouse are more likely to report a personal history of high blood pressure, diabetes and higher levels of cholesterol.⁶⁴
- Women who spend nine or more hours a week caring for an ill or disabled spouse increase their risk of heart disease two-fold.⁶⁵

Caregivers have lower levels of self-care.

- Caregivers are less likely to engage in preventive health behaviors.⁶⁶
- Spousal caregivers who provide 36 or more hours per week of care are slightly more likely to smoke and consume more saturated fat.⁶⁷
- Compared to noncaregivers, women caregivers are twice as likely not to fill a prescription because of the cost (26% vs. 13%).⁶⁸
- Nearly three quarters (72%) of caregivers reported that they had not gone to the doctor as often as they should, and more than half (55%) had missed doctors appointments.⁶⁹
- Caregivers' self-care suffers because they lack the time and energy to prepare proper meals or to exercise. About six in ten caregivers in a national survey reported that their eating (63%) and exercising (58%) habits are worse than before.⁷⁰
- Caregivers in rural areas are at a greater disadvantage for having their own medical needs met due to difficulty getting to the hospital and doctor.⁷¹

Caregivers pay the ultimate price for providing care—increased mortality.

- Elderly spousal caregivers (aged 66-96) who experience caregiving-related stress have a 63% higher mortality rate than noncaregivers of the same age.⁷²
- In 2006, hospitalization of an elderly spouse was found to be associated with an increased risk of caregiver death.⁷³

Increasing Positive Health Outcomes for Caregivers

A large and growing body of evidence reveals that providing care for a chronically sick person can have harmful physical, mental, and emotional consequences for the caregiver.^{74, 75, 76, 77} As families struggle to care for others, their own health is put in danger. As a result, caregiver health is quickly becoming a public health issue that requires more focused attention from

health professionals, policy makers and caregivers themselves to ensure the health and safety of those individuals dedicating their lives to the care of others.

Increasing appropriate mental health services and medical care for family caregivers are important steps toward addressing caregiver health. Although caregiving can have a negative impact on caregivers' health and well-being, research demonstrates its effects can be alleviated at least partially by:

- *An assessment of family caregiver needs that leads to a care plan with support services;*^{78, 79}
- *Caregiver education and support programs;*^{80, 81, 82}
- *Respite to reduce caregiver burden;*^{83, 84, 85}
- *Financial support to alleviate the economic stress of caregiving; and*
- *Primary care interventions that address caregiver needs.*^{86, 87}

Improved recognition and treatment of physical and psychological symptoms among caregivers is a growing health concern and should be considered a public health priority. Keeping family caregivers healthy and able to provide care is key to maintaining our nation's long-term care system and, with the aging of the population, this issue will only grow more important in the coming decades.

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Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's and other debilitating health conditions that strike adults.

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