

Most people who need help with daily activities as a result of a disabling condition or illness get the care they need from family members or friends. Some receive help from paid caregivers who work for agencies or independently. Despite the significant physical and emotional demands of providing care, the overwhelming majority of caregivers are meeting the challenge; many are doing an excellent job. But reports of abuse by caregivers are not uncommon and appear to be on the rise. This fact sheet responds to frequently asked questions about caregiver stress and abuse.



What is a caregiver?

The term refers to anyone who routinely helps others who are limited by chronic conditions. "Formal" caregivers are volunteers or paid employees connected to the social service or health care systems. The term "informal caregiver" refers to family members and friends, who are the primary source of care for nearly three-quarters of the impaired older adults who live in the community. Caregivers assist with such basic tasks as bathing, dressing, preparing meals and shopping. Some have the added responsibilities of administering medications, making sure that an immobile person is turned frequently to avoid developing pressure sores, and other tasks related to the older person's illness or disability.

How large a problem is abuse by caregivers?

Although it is known that in 90% of all reported elder abuse cases, the abuser is a family member, it is not known how many of these abusive family members are also caregivers. Researchers have estimated that anywhere from five to twenty-three percent of all caregivers are physically abusive. Most agree that abuse is related to the stresses associated with providing care.

What is caregiver stress and why is it harmful?

Stress is often described as the body's "fight or flight" response to danger. When the body goes on "high alert" to protect itself, essential functions, like respiration and heart rate, speed up, while less essential functions, such as the immune system, shut down. Although the stress response is a healthy reaction, the body needs to repair itself once danger is removed. For caregivers, whose stress often results from fatigue and conflicts that never go away, their bodies never get a chance to heal. If the immune system isn't functioning fully, the caregiver is at greater risk for infections and disease. Some experts believe that stress causes hypertension, coronary disease or even premature death.

Do all caregivers experience stress?

Some stress is normal. In the past, it was believed that the more care a person provided, the more likely she was to experience stress. Now it is known that not all caregivers are created equal. Some, who provide high levels of care, experience no stress, while others who provide relatively little care experience high levels of stress. Many experts believe that these differences can be explained by subjective factors such as how caregivers feel about providing care, their current and past relationships to those they care for, and their coping abilities. Some caregivers find certain behaviors by care receivers to be particularly stressful, including aggression, combativeness, wandering and incontinence. Others report that they experience stress because they don't get enough rest, privacy, support or time for themselves.

Are all "stressed caregivers" at risk for becoming abusive?

It is true that some of the same factors that are believed to cause caregiver stress also raise the risk of abuse. For example, when the relationship between a caregiver and care receiver was poor to begin with, the caregiver is more likely to feel stress and to become abusive. But the link between caregiver stress and abuse is not yet fully understood, and more research is needed to understand what factors predict or contribute to caregiver abuse. Specific areas that need to be explored include how aggression by care receivers raises the risk of abuse, why some caregivers fear that they will become abusive, whether caregivers who are afraid of becoming abusive are more likely to actually abuse, and how caregivers' coping patterns play a role.

Are there "red flags" to watch for?

Drawing from what is currently known about caregiver abuse, the following factors may be cause for concern:

The caregiver:

- Fears that he will become violent
- Suffers from low self esteem
- Perceives that she is not receiving adequate help or support from others
- Views caregiving as a burden
- Experiences emotional and mental "burnout," anxiety or severe depression
- Feels "caught in the middle" by providing care to children and elderly family members at the same time
- Has "old anger" toward the care receiver that can be traced back to their relationship in the past



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The care receiver:

- Is aggressive or combative
- Is verbally abusive
- Exhibits disturbing behaviors such as sexual "acting out" or embarrassing public displays

The caregiver and the care receiver:

- Live together
- Had a poor relationship prior to the onset of the illness or disabling condition
- Are married and have a marital relationship that is characterized by conflict



What can be done?

Reducing the risk of elder abuse by caregivers will require the efforts of caregivers, agencies and the community.

Caregivers can:

- Get help. Making use of social and support services, including support groups, respite care, home delivered meals, adult day care and assessment services, can reduce the stress associated with abuse.
- Learn to recognize their "triggers," those factors that cause them the greatest stress or anxiety.
- Learn to recognize and understand the causes of difficult behaviors and techniques for handling them more effectively.
- Develop relationships with other caregivers. Caregivers with strong emotional support from other caregivers are less likely to report stress or to fear that they will become abusive.
- Get healthy. Exercise, relaxation, good nutrition and adequate rest have been shown to reduce stress and help caregivers cope.
- Hire helpers. Attendants, chore workers, homemakers or personal care attendants can provide assistance with most daily activities. Caregivers who cannot afford to hire helpers may qualify for public assistance.
- Plan for the future. Careful planning can relieve stress by reducing uncertainty, preserving resources and preventing crises. A variety of instruments exist to help plan for the future including powers of attorney, advanced directives for health care, trusts and wills.

Agencies can:

- Carefully screen caregivers and patients for the risk factors associated with caregiver abuse.
- Provide caregivers with information and support to lower their risk.

- Provide instruction to caregivers (through materials, classes, websites or support groups) in conflict resolution and how to deal with difficult behaviors such as violence, combativeness and verbal abuse.
- Promote better coordination between agencies that offer protection to victims and those that offer services to caregivers. This can be achieved through cross-disciplinary training, interagency protocols and multidisciplinary teams.

Concerned citizens can:

- Lend a hand to a caregiver who needs help.
- Report abuse. In most communities, Adult Protective Services (APS) is the agency that accepts and investigates reports. Look in the city or county government section of the telephone directory under "Aging Services" or "Social Services," or contact local Area Agencies on Aging.
- Advocate for public policy to increase the supply and scope of services available to caregivers.
- Volunteer. Volunteers can make friendly visits, serve as guardians or bill payers, or provide respite care.
- Arrange to have speakers make presentations on caregiving at churches, clubs or civic organizations.



RESOURCES

To learn more about preventing abuse by caregivers:

A Model Intervention for Elder Abuse and Dementia. This curriculum was designed for workers in the field of adult protective services and Alzheimer's Association personnel. It contains referral protocols to improve communication and promote cooperation among organizations that provide services to caregivers and those that provide protective services. It also includes assessment guidelines to help professionals identify individuals and families at risk. For more information, contact:

Office of Geriatric Medicine/Gerontology Northeastern Ohio Universities College of Medicine P.O. Box 95 Rootstown, Ohio 44272	Phone: (330) 325-6359 Fax: (330) 325-5907 Email: brp@neuoucom.edu
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Preventing Stress from Becoming Harmful: A Guide for Individuals Who Care for Persons with Dementia. This handbook, which is also available from the Office of Geriatric Medicine/Gerontology (see above), is a self-assessment guide to help caregivers identify their own risk of becoming abusive and offers suggestions for lowering risk. The handbook is available in English and Spanish versions.

To learn more about dementia and caregiving:

AARP

The nation's leading organization for people over the age of 50 has produced a variety of publications on caregiving, many of which are available on its website. These include *A Caregiver Guide to Information and Resources (Document # D16697)*.

601 E Street, N.W. Washington, DC 20049	Phone: (202) 434-AARP http://www.aarp.org/confacts/caregive/planning.html
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Family Caregiver Alliance

A national information center and pioneer in the development of caregiver services. FCA's website provides a wealth of information and online services for caregivers.

690 Market Street, Suite 600 San Francisco, CA 94104	Phone: (415) 434-3388 Email: info@caregiver.org http://www.caregiver.org
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Alzheimer's Association

The largest national voluntary health organization committed to finding a cure for Alzheimer's disease and helping those affected by it. State and local chapters provide services to people with the disease, their families and caregivers, and health care professionals. The Alzheimer Association's website contains a section for caregivers, which includes resource directories, instructions in behavior management, and information about the disease and its treatment.

919 North Michigan Avenue, Suite 1100 Chicago, Illinois 60611-1676	Phone: (800) 272-3900 http://www.alz.org
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National Aging Information Resource Center

Operated by the Administration on Aging of the U.S. Department of Health and Human Services, this site includes information on government-sponsored resources, national caregiver organizations, articles and links to other sites. <http://www.aoa.gov/NAIC/Notes/caregiverresource.html>

To learn more about elder abuse and how to report it:

The National Center on Elder Abuse

1225 I Street, N.W., Suite 725 Washington, D.C. 20005	Phone: (202) 898-2586 Email: NCEA@nasua.org http://www.elderabusecenter.org
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National Committee for the Prevention of Elder Abuse

1101 Vermont Ave. NW, Suite 1000 Washington DC 20005	Phone: (202) 682-4140 Fax: (202) 682-3984 Email: ncepa@erols.com http://www.preventelderabuse.org
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To find out about services in your community:

Area Agencies on Aging (AAA) provide or coordinate services for the elderly and their families. They also provide information on a variety of issues of concern to the elderly and caregivers, and help seniors and their families gain access to services. Look in the city or county government section of the telephone directory under "Aging Services" or "Social Services." You can also get the number from the Eldercare Locator at **(800) 677-1116. ■**

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**Caregiver
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