

*“Taking time out, away from the care of an impaired person, is one of the single most important things that you can do to make it possible for you to continue to care for someone.”*

*–Mace and Robins,  
The 36 Hour Day.*

### **Taking Care of the Caregiver**

Family caregivers of chronically ill older persons or those with disabilities are generous, compassionate individuals. They care for loved ones in the familiar surroundings of their own home or community. These caregivers are “on call” 24-hours a day, 7 days a week because they want to see their loved one remain in the comfort and security of their own environment. But at some point, even the caregiver needs a break, a rest, or a breather. The caregiver needs respite. Respite provides informal caregivers – usually relatives a break from their daily responsibilities.

Family caregivers save federal, state and local governments, which are faced with the challenge of covering health and long term care expenses of persons who are ill and have chronic disabilities, a great deal of money. If the work of caregivers had to be replaced by paid home care staff, the estimated cost would be \$45 - \$94 billion per year. In response to and in recognition of the distinct needs of caregivers, the Administration on Aging (AoA) of the U.S. Department of Health and Human Services is implementing a program that will soon begin to offer respite and other services to some caregivers who so desperately need a break.

### **The National Family Caregiver Support Program Offers Respite**

The enactment of the Older Americans Act Amendments of 2000 (Public Law 106-501) established an important program, the National Family Caregiver Support Program (NFCSP). Funded at \$125 million in fiscal year 2001, approximately \$113 million has been allocated to states to work in partnership with area agencies on aging and local and community service providers to put into place multi-faceted systems of support for family caregivers. A specific component of these systems is respite. That could include, for example, respite care provided in a home, an adult day-care center or over a weekend in a nursing home or an assisted living facility.

Research has confirmed the benefits of respite. A paper compiled by Drs. Dale Lund and Scott Wright – experts in the field of caregiving analysis -- states that respite benefits both caregivers and their loved ones. It further states that to be most effective, caregivers should consider accessing services *early* in their caregiving experience. Lund and Wright have found that caregivers need sufficient and regular amounts of respite, and it is important that the caregiver give sufficient thought as to how he or she wants to use that freed-up time, when and if it becomes available.

*\* Many caregivers experience immense stress and feelings of burden, high rates of depression, and feelings of anger and anxiety;*

*\* Caregiving can adversely affect one's physical health and ability to continue providing care – leaving two impaired persons, rather than one.*

*\* The emotional and physical strain of caring for a frail older relative is often exacerbated by worries over paying for care, particularly for nursing homes.*

*\* Research has shown that some caregivers must quit their jobs to give care, while others experience increased absenteeism, lower productivity at work, lost career opportunities, and loss of future earnings.*

*\* American Society on Aging*

Respite can cover a wide range of services *based upon the unique needs of the caregiver*. It might involve medical or social adult day care and/or a short-term stay in a nursing home or assisted living facility for the loved one; a home health aide or home health companion; a private duty nurse or adult foster care.

For the caregiver, personal respite varies as much as the individual and could mean, for example: giving the caregiver a short break to attend a doctor's appointment or to go shopping; allowing the caregiver the opportunity to nap, bathe, or otherwise rejuvenate him or herself; attending a church service or seeing a movie; taking a much-needed vacation; pampering oneself with a hair appointment or manicure; scheduling elective surgery; or simply visiting friends or relatives.

### **Listening to the Caregivers**

In developing the NFCSP, AoA conducted a series of roundtable discussions with caregivers of older persons who have chronic illnesses or disabilities. These discussions were held in more than 30 cities across the United States, and allowed AoA to gain a more complete understanding of the day-to-day challenges faced by families caring for their older relatives, and to obtain additional insights into the types of services and supports that would respond to the needs of these and other caregivers. It was clear after listening to these caregivers that respite is a necessity. Here's what some of the caregivers told AoA:

"I took a vow when we got married 54 years ago, and I intend to carry it out. My only fear is that I will die from exhaustion before she does, and who will care for her then?"  
--Caregiver husband; Chicago, IL

"It has been a challenge going through this alone. To be able to have someone help me ... for just one-half hour or one hour to put her [mother] in bed, or get her up in the morning ... this would be helpful."  
--Caregiver daughter; San Francisco, CA

"Respite is my number one need. I've been caring for Mom for seven years ... in that time, I have had one vacation for three days."  
--Caregiver daughter; Milwaukee, WI

Many caregivers noted hardships and problems including physical and mental strain and feeling burned out or overwhelmed. Some felt they did not have enough time or energy to meet the demands facing them and that caregiving takes away from their personal lives.

*Respite care addresses one of the most pressing needs identified by families . . . temporary relief.*

*A unique feature of respite care is the help it offers to both the caregiver and the care recipient.*

*Respite care can allow time to go to the doctor or the grocery store, participate in a support group, or attend a class to learn caregiving skills.*

*Researchers have suggested that respite care can relieve the burden of the caregiving situation and allow families to continue to care for loved ones who would otherwise be placed in a nursing home.*

AoA, through the state and area agencies on aging (AAA), adult day care centers, and some community- and faith-based organizations, offers respite services to caregivers. The degree and types of respite services offered are discretionary in each state and often vary widely from state to state.

**The National Aging Network.** Under the authority of the Older Americans Act, AoA leads a national aging network to plan, coordinate, and provide home and community and faith-based services to meet the unique needs of older persons and their caregivers. AoA's aging network includes: 56 State Units on Aging, 655 Area Agencies on Aging, 236 Tribal and native organizations representing 300 American Indian and Alaska Native Tribal organizations and 2 organizations serving Native Hawaiians, plus thousands of service providers, adult care centers, caregivers, and volunteers.

**Who to Contact for Help.** The local AAA is one of the first resources a caregiver should contact when help is needed. Almost every state has one or more AAA, which serve local communities, older residents, and their families. (In a few states, the State Unit or Office on Aging serves as the AAA.) Local AAA's are generally listed in the city or county government sections of the telephone directory under "Aging" or "Social Services."

**The Eldercare Locator.** AoA supports a nationwide, toll-free information and assistance directory called the Eldercare Locator, which can locate the appropriate AAA to help an individual needing assistance for their loved ones, relatives, or friends. Older persons and caregivers can call the Eldercare Locator at 1-800-677-1116, Monday through Friday, 9:00 a.m. to 8:00 p.m. Eastern Time.

Working in close partnership with its sister agencies in the U.S. Department of Health and Human Services, the AoA is the official Federal agency dedicated to policy development, planning and the delivery of supportive home and community-based services to older persons and their caregivers. The AoA works through the national aging network of 56 State Units on Aging, 655 Area Agencies on Aging, 236 Tribal and Native organizations representing 300 American Indian and Alaska Native Tribal organizations, and two organizations serving Native Hawaiians, plus thousands of service providers, adult care centers, caregivers, and volunteers. For more information about the AoA, please contact:

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