RESOURCES:

Administration on Aging Care Network:
www.aoa.gov/carenetwork/default.htm

Administration on Aging Alzheimer site:
www.aoa.gov/alz

State Units on Aging:
www.aoa.gov/aoa/pages/state.html

Information for older relative caregivers:
www.aoa.gov/naic/notes/grandparents-grandchildren.html

National Alliance for Caregiving
www.caregiving.org

The Alzheimer's Association:
www.alz.org

The Family Caregiver Alliance:
www.caregiver.org

Online caregivers newsletters:
http://caregiving.com

The National Family Caregiver Association:
www.nfcacares.org

AARP:
www.aarp.org

The Eldercare Locator 1-800-677-1116
www.eldercare.gov www.ec-online.net

Administration on Aging

The AoA is the lead federal partner for the national aging network of state and area agencies on aging, tribal organizations, service providers and volunteers, which administers programs to support the well-being, health and independence of older persons and their caregivers.

The National Family Caregiver Support Program

U.S. Administration on Aging
Department of Health and Human Services

The National Family Caregiver Support Program

A Word From The Assistant Secretary for Aging

On behalf of the Administration on Aging, I am proud that Congress entrusted us with the responsibility of the National Family Caregiver Support Program. As someone who took care of my aunts and both of my aging parents, I am very aware of the everyday challenges that face caregivers. I also know how important this program can be throughout the United States. That is why we must increase the awareness of the NFCSP throughout our communities to ensure all caregivers are aware of this program so they can take advantage of it when they need it.

This brochure is a large step towards that awareness. It recognizes several states, resources and links that provide support, information and a network of communication to caregivers. I hope you find the enclosed information useful as we at the AoA continue to build and improve upon the caregiver program.

- Josefina G. Carbonell

Who Are the Caregivers?

- Each caregiver experience is unique, but they share common experiences.
- In the absence of a spouse who is able to provide care, a daughter or daughter-in-law is most likely to assume the role of caregiver.
- Family members are the primary providers of long-term care.
- One person is usually the primary caregiver, although there may be other family and friends that help.

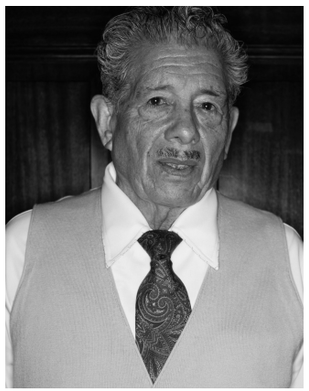
"Stages" in a Caregiving Career

- **STAGE 1 – Performing Caregiving Tasks**
  When a dependency situation emerges in which a family member or close acquaintance performs tasks designed to assist an older individual with routine activities previously performed without assistance.
- **STAGE 2 – Self-Definition as a Caregiver**
  When individuals come to view themselves as caregivers and incorporate this activity into their social or personal identity.
- **STAGE 3 – Performing Personal Care**
  When the caregiver begins providing personal care such as assistance with bathing, dressing, bladder and bowel evacuation, or other aspects of personal hygiene. Whereas the need for personal care marks the end of Informal caregiving for many children, it often signals an unambiguous start of caregiving for spouses.
- **STAGE 4 – Seeking Assistance and Formal Service Use**
  When the caregiver actively seeks out formal support services designed to assist informal caregivers. The frequent observation that many support services go unused likely reflects the fact that the services have been targeted to caregivers who have not yet reached this stage, which can be considered the "servable" moment.
- **STAGE 5 – Consideration of Nursing Home Placement**
  When the caregiver seriously considers placing the elder into a nursing home as an alternative to informal caregiving. When caregivers fail to seek services prior to seriously considering nursing home placement, there is little opportunity for services to play a preventive role.
- **STAGE 6 – Institutionalization**
  When nursing home placement occurs. As many dependent elders die without ever residing in a nursing home, not all caregivers reach this stage.
- **STAGE 7 – Termination of the Caregiving Role**
  When caregiving has an explicit end. There are three possible reasons: 1) death of the elder (or caregiver); 2) recovery of the elder; or 3) termination of the caregiving role (i.e.- caregiver quits). The significance of this stage is that it acknowledges that care by informal caregivers continues to be provided after the elder has been institutionalized.

**adapted from the "Seven Markers in the Caregiving Trajectory" by Rhonda J.V. Montgomery, Ph.D. Director ,Gerontology Center , University of Kansas*

Caregiver Diversity

Caregivers come from all ethnic, geographic and racial backgrounds. There are wide variations in the conditions of those who are receiving help, the kinds of assistance needed, the level of caregiver burden, and the self-perceptions of caregivers and their willingness to utilize the formal service delivery system.



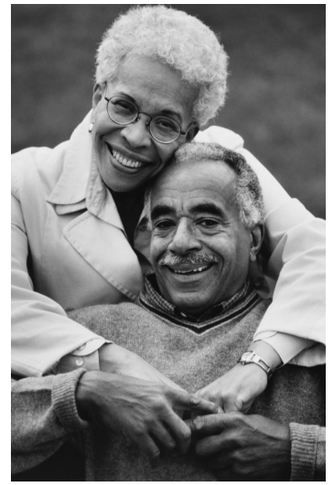
The following examples were made possible by the Administration on Aging funding innovative grants throughout the United States.

A community provider program was established to support Asian American and Pacific Islander caregivers through a community-based wellness, lifelong learning and information program. (CA)

The State Office on Aging is collaborating with the Community Legal Aid Society to develop a handbook addressing the legal concerns of grandparents and relative caregivers raising children. (DE)

An area agency on aging will test and implement a culturally proficient model of family caregiver support to meet the needs of Mexican-American caregivers and elders. (AZ)

The implementation of a project to establish regional training centers for caregivers of deaf older adults. (MA)



Money went to a community agency to develop a model health care and training intervention that targets African American daughters who are caregivers. (PA)

Several states have responded to the needs of rural caregivers by establishing lending libraries for training videos, comprehensive resource directories, books, pamphlets and other informational resource materials on caregiving.

Making A Difference for America's Caregivers

The National Family Caregiver Support Program (NFCSP) was established in November 2000. The NFCSP, administered by the Department of Health and Human Services' Administration on Aging, was officially launched by HHS Secretary Tommy Thompson in February 2001 with the release of $113 million in funds to states to begin its implementation. In addition, $5 million was released to 119 tribal organizations to support the caregivers of Native American elders, and approximately $6 million was awarded to fund 34 innovative grants and projects designed to test the effectiveness of caregiving programs across the nation.

In FY 2003, the National Family Caregiver Support Program was funded at $155.2 million. Of that amount, $5.5 million is for continued support of the Native American Caregiver Program. The NFCSP has served more than 275 thousand caregivers nationwide.

Since the enactment of the NFCSP, AoA's national network of State Offices on Aging, Area Agencies on Aging, tribal organizations and local community service providers, has displayed great diligence and creativity in implementing the law and providing much-needed services to caregivers of the elderly and those with disabilities.

In the first year, the network focused on the development of support systems and expanding the range of services to meet the diverse needs of caregivers. This has required them to be more flexible and more innovative in the delivery of services. Their efforts have resulted in new partnerships; improved access to services; outreach to special populations; and provision of services to respond to the unique needs of families.

Basic Services

Family caregivers provide an invaluable resource to their loved ones as well as to America. Their courage, compassion and dedication to family members and friends allow the elderly and persons with disabilities to remain in a loving environment, often at great cost - economic, physical and mental - to the caregiver. I am pleased that we are now able to assist caregivers and provide them with resources in their communities so that they may continue their support.

~HHS Secretary Tommy G. Thompson

The program calls for all states, working in partnership with area agencies on aging and local community-service providers to have five basic services for family caregivers, including:

1. Information to caregivers about available services
2. Assistance to caregivers in gaining access to supportive services
3. Individual counseling, organization of support groups, and caregiver training to caregivers to assist the caregivers in making decisions and solving problems relating to their caregiving roles
4. Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities
   - In-home respite care
   - Adult day services
   - Institutional respite on an intermittent, occasional or emergency basis
5. Supplemental services, on a limited basis, to complement the care provided by caregivers
   - Home modifications
   - Assistive technologies
   - Emergency response systems
   - Equipment/supplies
   - Transportation

In Florida, AoA funds were awarded to a service provider to establish and evaluate a multi-faceted project on end-of-life issues, providing hospice, palliative care professionals and family caregivers with in-depth training on caregiver concerns.

In Kentucky, the Lake Cumberland Area Agency on Aging assisted three siblings who assumed care of their mother with Alzheimer's disease and provided care to their father in his last few months of life. Counseling, support groups, adult day care and respite services were provided to assist them during those difficult days.

Eligible Populations of Caregivers

Family caregivers of older adults (age 60 years and older); and grandparents and relative caregivers of children not more than 18 years of age (including grandparents who are sole caregivers of children and those individuals who are affected by mental retardation or who have developmental disabilities). The statute requires states to give priority consideration to:

1. persons in greatest social and economic need (with particular attention to low-income, individuals); and 2) older individuals providing care and support to persons 18 and under with mental retardation and related developmental disabilities.

The D.C. Office on Aging provided emergency respite care for one week to a family whose caregiver was killed on September 11th at the Pentagon. NFCSP funds were used to make special provisions to care for the elderly mother in a nursing home to allow the family to make funeral arrangements for the caregiver and alternative plans for her future.

Why is the Program Needed?

Families, not social service agencies, nursing homes or government programs, are the mainstay of long term care (LTC) for older persons in the United States. The degree of caregiver involvement has remained fairly constant for more than a decade, bearing witness to the remarkable resilience of the American family in taking care of its older persons. This is despite increased geographic separation, greater numbers of women in the workforce, and other changes in family life.

Statistics:

More than 22.4 million U.S. households are serving in family caregiving roles for persons over the age of 50, and that number will increase rapidly as the population ages, and as medical science continues to extend life.

Costs:

The contribution of America's caregivers to the nation's health care system is valued at $257 billion annually, compared to $32 billion for home care and $92 billion on nursing home care. Caregiver services significantly reduce costs to Medicare, Medicaid, and private payers.