Family Caregivers: Our Heroes on the Frontlines of Long-Term Care

Family and informal caregivers are the backbone of our nation's long-term care system -- coordinating and providing care for millions of Americans. Caregivers provide assistance to family members and friends who experience limitations in activities of daily living (ADLs), such as bathing, dressing, eating, and toileting. They also provide assistance in instrumental activities of daily living (IADLs), such as meal preparation, medication management, and transportation. The unpaid and informal care they provide is the primary source of assistance for disabled individuals in the community. During the next few decades, the demand for family and informal caregivers will continue to increase as the population ages, medical science continues to extend life, and workforce shortages continue in the long-term care sector.

Unfortunately, a significant number of family caregivers describe their own health as "fair to poor". Recent research findings suggest that:

- The combination of loss, prolonged distress, and the physical demands of caregiving hurts the health of caregivers, resulting in more vulnerability to infectious diseases, such as colds and flu, and chronic diseases, such heart disease, diabetes, and cancer;
- o Elderly caregivers, who themselves may have a history of chronic illness and are experiencing stress related to caregiving, have a 63% higher mortality rate; and
- o Depressive symptoms are twice as common among caregivers as among the general population.

Researchers have also shown that caregivers are less likely than peers of the same age to engage in health-promoting behaviors that are important for chronic disease prevention and control. Some barriers for family caregivers, which often prevent their participation in health promotion and disease prevention activities, include:

- o The guilt that caregivers may feel by taking time out to care for themselves;
- o Competing demands on caregivers' time;
- o Ability to provide and availability of respite care; and
- o Availability and access to health promotion services, education, and information.

The Department of Health and Human Services (HHS) has been very active in helping to provide needed health promotion and disease prevention services to family caregivers through various research and programmatic efforts. These efforts include information for family caregivers, links to respite care and services in many communities, and educational materials on many disease prevention and health promotion topics.

- o Administration on Aging http://www.aoa.gov
- o National Family Caregiver Support Program http://www.aoa.gov/caregivers
- o National Institute on Aging http://www.nia.nih.gov
- o Centers for Disease Control and Prevention http://www.cdc.gov/nccdphp/dnpa
- o HHS Office on Disability http://www.hhs.gov/od
- o Centers for Medicare and Medicaid Services http://www.cms.hhs.gov/partnerships/tools/materials/caregiversresources/default.asp

Important Caregiver Facts

- Today, 22.4 million households are involved in providing care to persons aged 50 and older. These households are expected to increase to 39 million by 2007.
- More than 2.3 million grandparents are responsible for raising one or more of their grandchildren.
- Over 50% of all caregivers are employed on a full-time basis. Caregivers of individuals aged 65 and over, most often adult children, spend an average of 20 hours per week providing care. And, over 50% of all employed caregivers experience a conflict between work and caregiving.
- The value of the care provided by family caregivers was moderately estimated to be \$257 billion in 2000.

Related Links

- → Event Overview (http://aspe.hhs.gov/daltcp/CaregiverEvent/overview.pdf)
- → Event Agenda (http://aspe.hhs.gov/daltcp/CaregiverEvent/agenda.pdf)
- → Event Summary (http://aspe.hhs.gov/daltcp/CaregiverEvent/summit.pdf)
- → A Special Letter from Mrs. Nancy Reagan to Family Caregivers (http://aspe.hhs.gov/daltcp/CaregiverEvent/letter.pdf)
- → Frequently Asked Questions concerning Family Caregiving (http://aspe.hhs.gov/daltcp/CaregiverEvent/faq.pdf)
- → An Overview of Programs and Initiatives Sponsored by DHHS to Promote Healthy Aging: A Background Paper for the Blueprint on Aging for the 21st Century Technical Advisory Group (TAG) Meeting (http://aspe.hhs.gov/daltcp/CaregiverEvent/programs.pdf)
- → A Compendium of Intervention and Descriptive Studies Designed to Promote the Health of Caregivers for Older Adults (http://aspe.hhs.gov/daltcp/CaregiverEvent/compendium.pdf)

NOTE: HTML versions of all Caregiver Event material is also available from http://aspe.hhs.gov/daltcp/reports-e.shtml#DALTCP5, or Hard Copies can be mailed to you by emailing your request to webmaster.DALTCP@hhs.gov.