

FREQUENTLY ASKED QUESTIONS: FAMILY CAREGIVING

IMPACT OF FAMILY AND INFORMAL CAREGIVING TO OUR NATION

How many family caregivers provide help to loved ones in the US?

- o 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.

Who are family and informal caregivers?

- o Family caregivers are spouses, adult children and other relatives and friends.
- o Approximately 38% of informal care is in the form of adult children caring for aging parents.
- o Women are more likely to provide informal care.
- o The average caregiver is age 46, female, married and working outside the home.
- o The average age of primary caregivers of older persons is 60 years old. Half are 65 or older and slightly over one-third of primary caregivers are between the ages of 45 and 64.
- o Both men and women provide informal care. However, up to age 70, women are more likely to be caregivers and to provide more hours of care, to provide more care over longer periods and to care for more than one person.

How important is family or informal caregiving in the provision of long-term care?

- o Family caregivers have always been the main source of the long-term care services here in the United States.
- o Informal care plays a significant role in preventing or delaying the need of a disabled elder to go into a nursing home.
- o Approximately 95% of all older adults who experience limitations in their daily activities have family members involved in the personal care.
- o As disability increases, elders receive more and more informal care. 86% percent of elders at greatest risk of nursing home placement live with others and receive an average of 60 hours of informal care per week, supplemented by little over 14 hours of assistance from paid helpers.
- o The degree of family caregiver involvement has remained fairly constant over more than a decade, bearing witness to the remarkable resilience of the American family in caring for older adults, despite increasing geographic separation, greater numbers of women in the workplace, and other changes in family life.
- o Recent changes in the health care delivery system have led to shorter hospital stays, increased nursing home costs, and workforce shortages in the long-term care sector. Given that the shortage of paraprofessionals in all long-term care settings is likely to increase in the years to come, an even larger proportion of caregivers will likely need to take care of frail older family members at home.
- o The number of caregivers will only continue to rise rapidly as the population ages, and medical science continues to extend life.

What type of care do caregivers provide?

- o Caregivers of individuals aged 65 and over spend an average of 20 hours per week providing care.
- o Family caregivers provide assistance in accomplishing both Activities of Daily Living (ADLs) for 2.3 million elders and Instrumental Activities of Daily Living (IADLs) for 2.2 million elders.
- o Family caregivers may provide ADL assistance to help with bathing, dressing, eating, mobility, transferring/lifting, and toileting.
- o Assistance with IADLs may include help with meal preparation, medication management, money management, use of the telephone, and transportation.

How much does family caregiving save our nation in long-term care costs?

- o The economic value of informal and family caregiving was moderately estimated to be valued at \$257 billion in 2000.

What are the other typical commitments of family caregivers?

- o Over half of all caregivers are employed on a full-time basis. The National Alliance for Caregiving projects that by 2007, the total number of employed caregivers in the US is expected to increase to nearly 15.6 million working Americans or roughly 10% of all employed workers.

What impact does caregiving have on the employers of family caregivers?

- o For employed caregivers, there are increased stress-related illnesses, leading to greater use of employee health benefits, and additional health care costs for the employer.
- o Approximately 2/3 of working caregivers report that there are work conflicts resulting from unpaid leaves of absence.
- o As a result, the impact on their work may include decreased productivity, increased absenteeism, increased turnover, and the loss of between 5-12 day of work annually.
- o Such adverse impacts translate into an annual cost of approximately \$29 billion or \$1142.50 per employee.
 - Replacement costs for employees who quit in any year because of their caregiving responsibilities amounted to \$4.9 billion dollars.
 - Costs due to absenteeism in any year amounted to \$398 million.
 - Costs due to partial absenteeism in any year were estimated to be \$488 million.
 - Costs due to workday interruptions were estimated to be \$3.7 billion per year.
 - Costs in lost productivity due to eldercare crises were estimated to be over \$1 billion per year.
 - Costs for the supervisor to provide emotional support, arranging coverage for absent and late workers, counseling about benefits, and dealing with work disruptions was estimated to be \$805 million per year.
 - The total annual costs to U.S. employers, based on the sum of the six individual costs shown above for employed caregivers who provided more 9 or more hours of caregiving per week was estimated to be \$11.4 billion per year.

- If all employed caregivers were included in this estimate (i.e., those who provided up to 9 hours per week of caregiving), the total annual costs to U.S. employers was estimated to exceed \$29 billion per year.

HEALTH AND WELL-BEING OF FAMILY AND INFORMAL CAREGIVERS

What impact does caregiving have on the health and well-being of caregivers?

The cost of care to the caregiver -- in emotional, physical and financial stress and in time can be quite significant. Research has suggested that the combination of loss, prolonged distress, the physical demands of caregiving, and biological vulnerabilities of older caregivers may compromise their physiological health and increase their risk for physical problems, leading to increased mortality.

- o Caregiving is physically demanding and can tax the health of caregivers, many of whom are older persons themselves.
- o Caregiving responsibilities impose a heavy emotional strain and can often result in stress and depression. Such emotional strain, accompanied with the physical demands of caregiving, has been shown to be an independent risk factor for mortality among older adults.
- o Elderly caregivers with a history of chronic illness themselves who are experiencing caregiving related stress have a 63% higher mortality rate than their non-caregiving peers.
- o Caregivers of older persons have been shown to be less likely than non-caregiving peers of the same age to engage in health-promoting behaviors. Some unhealthy behaviors include sleep deprivation, poor eating habits, failure to exercise, failure to stay in bed when ill, and postponement of or failure to make medical appointments. Family caregivers are also at increased risk for excessive use of alcohol, tobacco and other drugs for depression.

What adverse mental and physical health concerns are experienced by family caregivers?

- o Researchers studying caregivers of spouses with dementia obtained blood samples and found that a chemical called Interleukin-6 sharply increased in the blood of stressed caregivers when compared with the blood of other people of similar ages, but not living under the stress of constant caregiving. Previous studies have linked Interleukin-6 with several diseases, including heart disease, arthritis, osteoporosis, type-2 diabetes, and certain types of cancer.
- o Data have 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.
- o Depressive symptoms are twice as common among caregivers as among the general population.

What issues and concerns make it difficult for family caregivers to be healthy?

Several actual and/or perceived barrier prevent many caregivers from engaging in health promotion and disease prevention activities. These may include:

- o Lack of available and access to health promotion services, supports for caregivers, health information/education, and respite care;
- o Lack of motivation to take care of own needs;
- o Inability to pay for needed formal caregivers services;
- o Feelings of guilt for taking time out from the caregiving role, especially when all of the burden of care rests solely on them;
- o Competing demands on the caregivers' time (including job, children, etc.);
- o Extended time in the caregiving role (number of years as a caregiver);
- o Increased intensity of caregiving activity (number of hours of caregiving provided/week);
- o Distant or poor quality relationship with the care recipient;

What common strategies do intervention programs utilize to the help the caregivers alleviate the mental and physical-related stress and it's impact on their health?

Effective tools to encourage family caregivers to engage in more beneficial health include:

- o Emphasize that it is not selfish to focus on your own health and desires when you are a caregiver -- it's also an important part of the job.
- o Reduce personal stress by recognizing warning signs early; acknowledge your feelings, identifying sources of stress, identifying what can and cannot be changed, and take action.
- o Set goals, with the necessary action steps, for something to be accomplish over a specified length of time (i.e., 3 to 6 months). Examples of goals may include taking a break from caregiving, getting help with caregiving tasks and feel more healthy (with action steps to potentially include a physical check-up, exercise, more sleep, etc.)
- o Seeking solutions by identifying the problem, listing the possible solutions to the problem, evaluating the results of a chosen solutions and rely on the outside resources if needed.
- o Asking for and accepting help.
- o Being prepared when talking to a physician about your own health by preparing questions ahead of time, enlisting the help of the nurse, making sure your appointment meets your needs, taking someone with you, and using assertive language.

Why is the health and well-being of caregivers important?

Recent research has shown that there is a link between caregiver strain and poor caregiver health outcomes. Specifically:

- o The health of caregivers was compared with that of people of similar ages not living under the stress of constant caregiving. Blood tests showed that a chemical called Interleukin-6 sharply increased in the blood of the stressed caregivers compared with blood of the others in the test. Previous studies have associated IL-6 with several diseases, including heart disease, arthritis, osteoporosis, type-2 diabetes and certain cancers.

- o For the Caregiver Health Effects Study, the focus was on examining the relationship between caregiving and mortality. Four groups of individuals were classified, based on their caregiver status and the emotional or mental strain involved with taking care of a disabled spouse. Study participants were followed for an average of 4.5 years. After more than four years of follow-up, participants who were providing care and experiencing caregiver strain had a relative mortality risk 63% higher than the relative risk for those whose spouses were not disabled.
- o Caregivers have, and continue to be the major coordinators and providers of everyday long-term care. During the next few decades, the demand for informal caregivers will rapidly increase even further as the number of older persons needing assistance to remain independent increases dramatically. The data described above suggest a pressing need for effective models to encourage caregivers to engage in activities that will benefit their own health and well-being.

While there are various known and established health promotion and disease prevention programs and interventions that currently target aging adults, less is known about the availability of programs and services that promote disease prevention within the informal care population of the elderly. Because the Department of Health and Human Services recognizes the impending shortage of informal caregivers and the importance of encouraging caregivers to take care of themselves in order to provide ongoing support their disabled or ill family members at home, it has funded the Health Promotion and Aging Study: Blueprint for Change in the 21st Century.

- o Part of this study was designed to provide information on state and local initiatives that have developed promising programs to support, educate and motivate caregivers of persons aged 60 and older to maintain and improve their health and functioning.
- o Another part of this study was developed to plan and conduct a Caregiver Summit to highlight the important role that caregivers play and examine and discuss health promotion, disease prevention, and health education programs available to promote their well-being.

HHS-SPONSORED AND PRIVATE ACTIVITIES

What HHS-sponsored programs and activities provide support for family caregivers?

- 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>

What is the National Family Caregiver Support Program and how does it support HHS mission to help family caregivers?

- o The National Family Caregiver Support Program was created as a result of the Older Americans Act Amendments of 2000.
- o Currently funded at \$155.2 million, this program has reached almost 4 million caregivers nation-wide. It has provided direct assistance to about 436,000 caregivers.
- o 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. These services include:
 - Information to caregivers about available services;
 - Assistance to caregivers in gaining access to services;
 - Individual counseling, organization of support groups, and caregiver training to caregivers to assist the caregivers in making decision and solving problems relating to their caregiving roles;
 - Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
 - Supplemental services, on a limited basis, to complement the care provided by caregivers.
- o Efforts of the program 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.
- o The ElderCare locator can help caregivers find out the location of their agency on agency on aging: <http://www.eldercare.gov> or 1-800-677-1116

What programs and research studies are in place to help family caregivers stay healthy and/or avoid illness?

Caregiver Resources

- o Administration on Aging: <http://www.aoa.gov>.
- o Family Caregiver Alliance, National Center on Caregiving: <http://www.caregiver.org>.
- o National Alliance for Caregiving: <http://www.caregiving.org>.
- o National Family Caregivers Association: <http://www.nfcacares.org>.
- o Today's Caregiver Magazine: <http://www.caregiver.com>. Site includes topic specific newsletters, online discussion lists, and back issue articles.
- o FamilyCare America: <http://www.familycareamerica.com>. Offers varied resources to meet caregivers' specific needs, in their own localities, provides caregiver support, solution sharing, and discussion forums.

Respite Services

- o Easter Seals: <http://www.easter-seals.org>. Provides a variety of services at 400 sites nationwide for children and adults with disabilities, including adult daycare and in-home care.
- o National Council on the Aging, Inc.: <http://www.ncoa.org>.
- o National Adult Day Services Association: <http://www.nadsa.org>. Provides information about locating adult day care centers in your local area.

- o Interfaith Caregivers Alliance: <http://www.nfive.org>. Provides respite support and a variety of other services through local congregations working together. There are currently 1300 programs throughout the country.
- o Shepherd's Centers of America: <http://www.shepherdcenters.org>. Provides respite care, telephone visitors, in-home visitors, nursing home visitors, home health aides, support groups, adult daycare, and information and referrals for accessing other services available in the community. There are currently 75 centers around the country.

Intervention Studies

- o Family Caregiving Initiative: Making Room for Caregivers. Sponsored by the United Hospital Fund. Contact information: Carol Levine, Executive Director, United Hospital Fund. Phone: (212) 494-0755 (direct line). Website address: <http://www.uhfny.org>.
- o Health First Study: Caregivers Take Time to Stay Active. Sponsored by the National Institute on Aging. Contact information: Cathleen Connell, Associate Professor, University of Michigan. Phone: (734) 647-3189. Email: Cathleen@umich.edu.
- o PREP: Family Based Care for Frail Older Persons. Sponsored by the National Institute on Aging, National Institute for Nursing Research, and Northwest Region of Kaiser Permanente. Contact information: Pat Archbold, Associate Professor, Oregon Health Sciences University. Phone: (503) 494-3840. Email: archbold@ohsu.edu.
- o REACH II: Resources for Enhancing Alzheimer's Caregiver Health. Sponsored by the National Institute on Aging and National Institute of Nursing Research. Contact information: Richard Schulz, Professor. University of Pittsburgh. Phone: (412) 624-4810. Email: rschulz@pitt.edu. Website address: <http://www.edc.gsph.pitt.edu/REACH2/public/about.html>.
- o Supporting Older African-American Caregivers: Assessing Needs, Building Skills, and Maintaining Health. Sponsored by the Administration on Aging. Contact information: Joan Klein, Director, Family Caregiver Support Program, Philadelphia Corporation for Aging. Phone: (215) 765-9000, ext. 4356. Email: jklein@pcaphl.org.
- o Teaching Healthy Lifestyles for Caregivers Study. Sponsored by the National Institute on Aging. Contact information: Abby King, Professor, Stanford University School of Medicine. Phone: (650) 723-6522. Email: King@stanford.edu.

Descriptive Studies

- o Caregiver Health Effects Study (CHES). Sponsored by the National Institute of Mental Health, National Institute on Aging, National Heart, Lung, and Blood Institute, and Oregon State University. Contact information: Richard Schulz, Professor. University of Pittsburgh. Phone: (412) 624-4810. Email: rschulz@pitt.edu.
- o Maine Primary Partners in Caregiving (MPPC) Program. Sponsored by the Administration on Aging. Contact information: Roberta Downey, Project Director. Eastern Area Agency on Aging. Phone: (207) 941-2865. Email: Redowney@eaaa.org.
- o Making the Link Program. Sponsored by the Administration on Aging. Contact information: Adrienne Dern, Program Director, National Association of Area Agencies on Aging. Phone: (202) 296-8130. Email: adern@n4a.org. Website address: <http://www.n4a.org>.

- o Powerful Tools for Caregiving. Sponsored by Legacy Health System, Mather Life Ways Foundation, Robert Wood Johnson Foundation, Administration on Aging, and several other foundations, community agencies and extension programs. Contact people: Daniel Kuhn (research questions), and Susan Rothas (program questions). Phone numbers: (847)-492 6813 for Daniel, and (847) 492-6809 for Susan. Email address for Daniel: Dkuhn@matherlifeways.com . Website address: <http://www.matherlifeways.com>.
 - o Rosalynn Carter Institute (RCI) and Johnson & Johnson Caregivers Program and the CARE-NET Project. Sponsored by RCI, Georgia Southwestern State University in Americus, Johnson and Johnson, the Administration on Aging and private donors. Contact information: Rhonda Tally, RCI Executive Director. Phone: (229) 928-1234. Email: rci@rci.gsw.edu. Website: <http://www.rci.gsw.edu>.
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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>)
- ➔ One-Page Fact Sheet on Family Caregivers (<http://aspe.hhs.gov/daltcp/CaregiverEvent/factsheet.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.