



## **Innovative Employer Caregiving Programs**

### **Satellite Broadcast Resource List**

The “Innovative Employer Caregiving Programs” Broadcast is presented by the U.S. Department of Health and Human Services (DHHS) New Freedom Initiative (NFI) Subcommittee on Caregiving. The Committee was established to work across DHHS and includes representation from all agencies within the Department as well as other Federal partners.

The resources contained in this document are drawn from numerous sources by NFI Subcommittee on Caregiving members, speakers and other stakeholders. This Resource List is not intended to be exhaustive or all-inclusive. CMS does not endorse specific products or services of non-federal institutions

#### **Table of Contents**

New Freedom Initiative.....	1
Alzheimer's Disease Support.....	2
Caregiver & Employer Resources .....	2
Extra Help - Social Security Administration .....	13
Grant Programs .....	13
Long Term Care .....	14
Medicare & Medicaid .....	14
State & Local Resources.....	16
Veterans Support.....	17

#### **New Freedom Initiative**

*On February 1, 2001, President Bush announced the New Freedom Initiative as part of a nationwide effort to remove barriers to community living for people with disabilities. The New Freedom Initiative is a comprehensive plan that represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives and participate fully in community life.*

*New Freedom Initiative Website*

<http://www.hhs.gov/newfreedom/>

This website contains information on the New Freedom Initiative.

*New Freedom Initiative Subcommittee on Caregiving*

[http://www.hhs.gov/od/about/fact\\_sheets/fs4\\_caregiving.html](http://www.hhs.gov/od/about/fact_sheets/fs4_caregiving.html)

This web page, housed on the HHS Office of Disability website, contains background information on the New Freedom Initiative Subcommittee on Caregiving.

## **Alzheimer's Disease Support**

*Alzheimer's Disease Demonstration Grants to States (ADDGS) "Resource Room"*

<http://www.aoa.gov/alz>

The Alzheimer's Resource Room is where families, caregivers, and professionals can find information about The Alzheimer's Demonstration Program, including: where you can turn for support and assistance, and providing services to caregivers.

## **Caregiver & Employer Resources**

### **❖ Caregiver Health**

*Caregiver Depression*

[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1013](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1013)

This policy brief discusses the factors contributing to high levels of clinical depression among family caregivers, describes barriers to treatment and promising approaches to alleviating symptoms, and suggests policies to support family caregivers.

*Strength for Caring (Johnson & Johnson)*

*Strength for Caring is an online resource and community for family caregivers. It is part of The Caregiver Initiative, created by Johnson & Johnson Consumer Products Company.*

*Caring for Caregivers*

<http://www.strengthforcaring.com/manual/stress-relieve-stress-management-tips/caring-for-caregivers/>

This website contains information and resources to help care for caregivers who may be experiencing physical illness, depression, grief, and other changes.

### **❖ Long Distance Caregiving**

*Handbook for Long-Distance Caregivers: An Essential Guide for Families and Friends Caring for Ill or Elderly Loved Ones*

[http://www.caregiver.org/caregiver/jsp/content/pdfs/op\\_2003\\_long\\_distance\\_handbook.pdf](http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2003_long_distance_handbook.pdf)

This booklet offers a roadmap for those new to the challenges of caring from afar for ill or elderly loved ones. It includes information on: how to assess your care situation; develop a care team; hold a family meeting; access community organizations and private agencies; and balance work and caregiving.

*Miles Away: The MetLife Study of Long-Distance Caregiving*

<http://www.caregiving.org/data/milesaway.pdf>

Family care from a distance is a fact of life for millions of Americans. Living at a distance from an aging parent or grandparent can make care provision a complex and difficult challenge. And, for many of those who are caring at a distance, these challenges affect not only the personal activities of the care providers, but their work and career as well. In 2004, the MetLife Mature Market Institute and the National Alliance for Caregiving undertook a survey of long-distance caregivers to examine these challenges.

*Since You Care: Long Distance Caregiving*

<http://www.metlife.com/WPSAssets/30520778401118179212V1FLong%20Dist%20Caregiving.pdf>

This is one in a series of guides for family caregivers prepared by the MetLife Mature Market Institute in cooperation with the National Alliance for Caregiving and MetLife's Nurse Care Managers.

## ❖ Caregiver Programs & Services

*ABCs of Problem Behaviors – Probes for the 'ABC Process'*

<http://www.cmha.ua.edu/Behavioral%20Prescription%20pages.pdf>

This document is a tool for caregivers to learn how to deal with problem behaviors in their loved ones.

### Administration on Aging

*The mission of the Administration on Aging is to assist elderly individuals maintain their independence and dignity in their homes and communities through comprehensive, coordinated, and cost effective systems of home and community-based long-term care across the U.S. AoA works in close collaboration with the Aging Network of states, Area Agencies on Aging, and local community service provider agencies- the most visible, trusted community resources for information access and services.*

*National Family Caregiver Support Program (NFCSP) "Resource Room"*

<http://www.aoa.gov/>

The Caregiver Resource Room is where families, caregivers, and professionals can find information about the National Family Caregiver Support Program, including: where you can turn for support and assistance, and providing services to caregivers.

*The Native American Caregiver Support Program (NACSP) Fact Sheets*

<http://www.aoa.gov/>

*The Older Americans Act Amendments in 2000 also created the Native American Caregiver Support Program (NACSP). This webpage contains several American Indian and Alaska Native-specific fact sheets.*

### American Red Cross

*Since its founding in 1881 by visionary leader Clara Barton, the American Red Cross has been the nation's premier emergency response organization. As part of a worldwide movement that offers neutral humanitarian care to the victims of war, the American Red Cross distinguishes itself by also aiding victims of devastating natural disasters. Over the years, the organization has expanded its services, always with the aim of preventing and relieving suffering.*

*Today, in addition to domestic disaster relief, the American Red Cross offers compassionate services in five other areas: community services that help the needy; support and comfort for military members and their families; the collection, processing and distribution of lifesaving blood and blood products; educational programs that promote health and safety; and international relief and development programs.*

*Health and Safety Services: Family Caregiving*

<http://www.redcross.org/services/hss/care/family.html>

The purpose of the Family Caregiving Program is to help participants gain an understanding of what is involved in caring for a loved one and to let them know how to provide that care. Family Caregiving consists of nine one-hour modules covering topics such as home safety, eating, personal care and others.

*Be Red Cross Ready Safety Series Vol. 1: Family Caregiving*

<http://american.redcross.org/site/PageServer?pagename=FamilyCaregiving&JServSessionIdr007=p0i4oj1us1.app194a>

Family Caregiving is a quick reference guide with a companion DVD to assist individuals to care for an elderly or chronically ill loved one, learn basic caregiving skills and how to reduce stress and balance the demands of work and home. The guide costs \$24.95. Topics included in the guide are:

- Home safety
- Caregiving skills
- Body mechanics
- Personal care
- Healthy eating
- Caring for the caregiver
- Legal and financial issues
- Dementia
- Caregiving Resources

*Caregiver Toolkit*

[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1695](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1695)

This is a step-by-step resource filled with practical information and resources. It's designed for program administrators and practitioners to: (1) sharpen your awareness of family caregivers as an at-risk population in need of assessments to determine their own physical, emotional and financial problems and (2) give you new knowledge and skills so you can create and put to use a caregiver assessment that works in your particular practice setting.

*Evercare™ Solutions for Caregivers*

[www.EvercareHealthPlans.com/Caregivers](http://www.EvercareHealthPlans.com/Caregivers)

Evercare™ Solutions for Caregivers helps ease the burden of caregiving so that working caregivers can remain productive at work. Through a network of Care Advocates and services, caregivers have access to the resources and support they need the most to care for their loved one. Evercare connects caregivers to our nationwide network of Professional Care Managers, a group of credentialed experts and registered nurses who provide in-person advice and support as Care Advocates. Services offered include: face-to-face needs assessment of medical and non-medical needs; development of a personalized plan for future care; identification of safe and appropriate services, including in-home support; and evaluation and monitoring of both the caregiver's and the loved one's progress.

### *Powerful Tools for Caregivers*

<http://www.uwex.edu/ces/flp/caregiving/education/powerfultools/index.cfm>

Powerful Tools for Caregivers (PTC) is an educational program designed to support family caregivers of older adults in a way that enhances their well being as they care for others. Extension has provided significant leadership in the dissemination of Powerful Tools for Caregivers by expanding the program in all 50 states. To become a class leader or master trainer for PTC, contact Legacy Caregiver Services' Kathy Shannon [kshaon@lhs.org](mailto:kshaon@lhs.org) or at 503-413-6778 or Leslie Congleton [lcongle@lhs.org](mailto:lcongle@lhs.org) or at 503-413-7032.

## **❖ Publications, Research & Web Sites**

### AARP

*AARP is a nonprofit, nonpartisan membership organization for people age 50 and over. AARP is dedicated to enhancing quality of life for all as we age. AARP leads positive social change and delivers value to members through information, advocacy, and service.*

### *AARP Caregiving Website*

<http://www.aarp.org/caregiving>

This website for family caregivers includes tip sheets, articles, interactive features, links to social networking features such as support groups and discussion boards, and many other resources for those who are caring for a loved one now or who may do so in the future.

### *Economic Value of Family Caregiving*

[http://www.aarp.org/research/housing-mobility/caregiving/ib82\\_caregiving.html](http://www.aarp.org/research/housing-mobility/caregiving/ib82_caregiving.html)

This research provides state and national level data on the estimated economic value of informal caregiving, estimated at \$350 billion in 2006. The report also discusses financial impact of caregiving on the caregivers themselves, compares the economic value of family caregiving to other benchmarks in order to underscore the magnitude of these unpaid contributions, presents estimates of productivity losses to U.S. businesses from caregiving, and highlights the critical role that family caregivers play in the nation's long-term care system.

### *Prepare to Care*

[http://www.aarp.org/about\\_aarp/aarp\\_foundation/programs\\_services/prepare\\_to\\_care.html](http://www.aarp.org/about_aarp/aarp_foundation/programs_services/prepare_to_care.html)

"Prepare to Care" is a planning guide for families to help them plan for future caregiving responsibilities, find public benefits, other free and low cost resources, and free AARP Foundation programs in advance. This guide can also be useful for employers to share with their employees, for media, non-profit organizations and others who may work with family caregivers. Email [benefitsoutreach@aarp.org](mailto:benefitsoutreach@aarp.org) to order guides for your employees, or to sign up for Prepare to Care Workplace training.

### *A Family Caregiver's Guide to Hospital Discharge Planning*

<http://www.caregiving.org/pubs/brochures/familydischargeplanning.pdf>

<http://www.caregiving.org/pubs/brochures/famdisplanesp.pdf> (Spanish)

This guide is a companion to a booklet for hospital discharge planners. Together they are intended to make discharge planning a little smoother by informing family caregivers of what to expect and by the discharge planner some insights about the family's perspective.

### *A National Public Health Road Map to Maintaining Cognitive Health*

<http://www.cdc.gov/aging/roadmap/index.htm>

"The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health" comes at a critical time when scientific interest in cognitive health is beginning to meet the burgeoning demand of the public in maintaining cognitive function. It sets in motion a course of action for establishing partnerships, making cognitive health a prominent public health issue, and preparing society for concerted efforts to maintaining the cognitive health of older Americans.

### *Alzheimer's Association*

[www.alz.org](http://www.alz.org)

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. The Alzheimer's Association provides information, education and support in numerous ways, including a 24/7 helpline, support groups, and online resources and support.

### *Caring for Those You Care About*

<http://www.aarp.org/caregiving>

"Caring for Those You Care About" is a set of tip sheets for family caregivers on a range of topics from hiring a home care worker to home modification, housing options, transportation, legal and insurance issues, and end-of-life care. This resource can help family caregivers directly and professionals who work with family caregivers. The tip sheets are available online at <http://www.aarp.org/caregiving>. You may order a CD (stock #C2133) or a binder (stock #D18186 English and D#18242 Spanish) containing the tip sheets by calling AARP at 1-888-687-2277.

### *Caring for Your Parents, The Complete Family Guide, Practical Advice You Can Trust From the Experts at AARP*

<http://www.aarp.org/books>

A newly updated AARP book titled "Caring for Your Parents, The Complete Family Guide, Practical Advice You Can Trust From the Experts at AARP" is available from AARP Publications. It was written by Editor-in-Chief Hugh Delehanty and AARP's Livable Communities Strategy Director Elinor Ginzler, with a foreword by Mary Pipher. It is available with a 35% discount.

### Centers for Disease Control and Prevention

<http://www.cdc.gov/aging/caregiving/index.htm>

*CDC is the nation's premier public health agency - working to ensure healthy people in a healthy world. The mission of CDC is "to promote health and quality of life by preventing and controlling disease, injury, and disability."*

### *Assuring Healthy Caregivers - A Public Health Approach to Translating Research into Practice: The RE-AIM Framework*

[http://www.cdc.gov/Aging/pdf/caregiving\\_monograph.pdf](http://www.cdc.gov/Aging/pdf/caregiving_monograph.pdf)

The issue of caregiving—with the exponential growth in the number of caregivers; the huge costs to society, families, and individuals; and the development of effective interventions to address caregiver burden and health—has become a public health priority of national concern. It is imperative that research and practice communities work together to translate evidence-based programs and policies into widespread practice. Application of the RE-AIM Framework can facilitate successful translation efforts and make a positive difference in the lives of caregivers and their families and friends.

CDC Morbidity and Mortality Weekly Report – “Characteristics and Health of Caregivers and Care Recipients - North Carolina, 2005”

<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5621a3.htm>

A caregiver screening question was administered in the North Carolina 2005 Behavioral Risk Factor Surveillance System (BRFSS) survey. This document contains the results.

*Promoting the Health and Well-Being of Caregivers for Older Adults.*

Responding to the challenges inherent in translating evidence-based caregiver interventions into the “real-world” settings, CDC’s Healthy Aging Program released a monograph titled “Assuring Healthy Caregivers. A Public Health Approach to Translating Research into Practice: The RE-AIM Framework” that introduces the application of the RE-AIM framework as a useful tool for addressing those challenges. Disciplined and continuous application of this framework can help practitioners and researchers anticipate pertinent issues as they engage in planning, conducting, and evaluating caregiver intervention programs and policies to promote the health and well-being of caregivers. The monograph illustrates the application of the RE-AIM framework to a leading caregiver intervention program, Alabama’s REACH Demonstration Project. Collaborators on this project include the Institute for Health Research at Kaiser Permanente Colorado and the Center for Mental Health and Aging at the University of Alabama.

Reference:

Centers for Disease Control and Prevention and the Kimberly-Clark Corporation (2008). *Assuring Healthy Caregivers, A Public Health Approach to Translating Research into Practice: The RE-AIM Framework*. Neenah, WI: Kimberly-Clark Corporation. Served as the author of the caregiving section.

*Corporate Eldercare Programs: Their Impact, Effectiveness and the Implications for Employers*

This report outlines the findings of an 18-month study examining the extent to which workplace caregiving programs helped the employees who used them. The study was designed and conducted by the National Alliance for Caregiving and the Center for Productive Aging, Towson University, program faculty and staff. It was funded by LifeCare, Inc., a privately owned specialty care services provider and longtime leader in the work/life industry.



LifeCare Study  
2008.pdf

Cooperative Extension System Publication on Aging Issues

[http://www.csress.usda.gov/nea/family/pdfs/aging\\_resources.pdf](http://www.csress.usda.gov/nea/family/pdfs/aging_resources.pdf)

In collaboration with CSRESS, Cooperative Extension System faculty have contributed information and resources to the development of the 2006-2007 Cooperative Extension System Resources, Contacts, and Collaborations: Aging Issues, with resources and contacts on aging issues organized by state. This e-publication includes the name and contact information for each of the partner institutions, as well as more detailed contact information for the heads of the aging education programs. This publication is updated annually.



### *Family Voices*

[www.familyvoices.org](http://www.familyvoices.org)

Resource Catalogue: <http://www.familyvoices.org/catalog.php>

Family Voices, a national grassroots network of families and friends, advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs; promotes the inclusion of all families as decision makers at all levels of health care; and supports essential partnerships between families and professionals. Family Voices is also the home of The National Center for Family/Professional Partnerships.

This site has information that includes information for advocates, caring for your child and health care financing issues.

### Family Caregiver Alliance

*Founded in 1977, Family Caregiver Alliance was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. FCA now offers programs at national, state and local levels to support and sustain caregivers. FCA seeks to improve the quality of life for caregivers through education, services, research and advocacy.*

### *National Center on Caregiving*

FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers. FCA publishes fact sheets and other resources on caregivers and the issues they face. Fact Sheets included:

- [Be Wise...Immunize](#) (Also available in: Spanish, Chinese, Russian, and Vietnamese)
- [Caregiver Health: A Population at Risk](#)
- [Caregiving & Depression](#)
- [Community Care Options](#)
- [Grief & Loss](#)
- [Taking Care of You: Self-Care for Family Caregivers](#)
- [Women and Caregiving: Facts and Figures](#)

### *Families and Work Institute*

<http://www.familiesandwork.org/>

Founded in 1989, Families and Work Institute is a nonprofit center dedicated to providing research for living in today's changing workplace, changing family and changing community. Their work has focused on four major areas: the workforce and workplace; education, care and community; parenting; and youth development.

### *Framing the Public Health of Caregiving*

<http://www.ajph.org/cgi/content/abstract/97/2/224> (Abstract)

This abstract conceptualizes caregiving as an emerging public health issue involving complex and fluctuating roles.



### *Friday's Child Newsletter*

<http://www.familyvoices.org/pub/fc/index.php>

Friday's Child is a bi-weekly e-newsletter containing information for existing and emerging family leaders on topics such as leadership, mentoring, partnering and team building. Each issue provides news and resources from the Family Voices network and the broader community of families and friends of children and youth with special health care needs.

### *Hospital Discharge Planning: Helping Family Caregivers through the Process*

<http://www.caregiving.org/pubs/brochures/DischargePlanner.pdf>

This guide is a companion to a booklet for family caregivers. Together they are intended to make discharge planning a little smoother by informing family caregivers of what to expect and by the discharge planner some insights about the family's perspective.

### *How Employers Can Support Working Caregivers (article with resources)*

[http://www.aarp.org/money/work/articles/how\\_employers\\_can\\_support\\_working\\_caregivers.html](http://www.aarp.org/money/work/articles/how_employers_can_support_working_caregivers.html)

### *League of Experienced Caregivers*

[www.familycaregivers.uwm.edu](http://www.familycaregivers.uwm.edu)

The League of Experienced Family Caregivers (LEFC) is a registry of family members who care for their spouses, parents, or other elderly relatives and who want to help other families by sharing information about their experiences as caregivers.

### *National Alliance for Caregiving*

*Established in 1996, the National Alliance for Caregiving is a non-profit coalition of more than 40 national organizations that focus on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.*

### *Evercare Study of Caregivers in Decline: A Close-Up Look at the Health Risks of Caring for a Loved One*

<http://www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf>

In 2004, the National Alliance for Caregiving and AARP conducted a national caregiver survey of adult caregivers in the U.S. Results showed that over 44 million Americans age 18 or older, or an estimated 21% of the adult population, provide care for an adult family member or friend age 18 or older. In this study, caregivers were asked two questions about their health, identical to CDC self-reported health questions. In the population as a whole, 9% of people report their health as only fair or poor. Yet, 17% of all caregivers in the national study reported their health as fair or poor, with 35% of those doing the most intense caregiving saying they have fair or poor health. In addition, 34% of those with only fair or poor health said that caregiving had made their health worse.

### *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*

<http://www.caregiving.org/data/Caregiver%20Cost%20Study.pdf>

This study estimates the productivity losses to U.S. business of employees who must make workplace accommodations as a result of caregiving responsibilities. These include costs associated with replacing employees, absenteeism, crisis in care, workday interruptions, supervisory time, unpaid leave, and reducing hours from full-time to part time.

### *Young Caregivers in the United States: Report of Findings from a National Survey*

<http://www.caregiving.org/data/youngcaregivers.pdf>

In 2003 the U.S. Administration on Aging awarded a grant to the National Alliance on Caregiving, in collaboration with the United Hospital Fund's Families and Health Care Project, to conduct the first national survey of child caregivers in this country. Until this study no national prevalence studies or large-scale studies of the impact of caregiving on children had been conducted in the U.S.

### National Cancer Institute

*The National Cancer Institute coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.*

### National Cancer Institute Website

<http://www.cancer.gov/>

The National Cancer Institute has produced three booklets on issues affecting caregivers of relatives with cancer. They include:

- [When Someone You Love Is Being Treated for Cancer](#)
- [When Someone You Love Has Advanced Cancer](#)
- [Facing Forward When Someone You Love Has Completed Cancer Treatment](#)

### Partners in Caregiving

<http://citra.org/Assets/documents/PIC%20final%20manual%20las%20edits.pdf>

Cornell Institute for Translational Research on Aging resource in support of and education with caregivers and families lead to improved elder care.

### State of the Science: Professional Partners Supporting Family Caregivers

<http://www.nursingcenter.com/ajnfamilycaregivers>

This special report on "Professional Partners Supporting Family Caregivers" distills what is known about the concerns of family caregivers and ways that nurses and social workers can better support them in caring for older adults. The report's wide-ranging articles and recommendations are the result of a groundbreaking "state of the science" symposium led by the AARP Foundation in partnership with American Journal of Nursing, the Council on Social Work Education, the Family Caregiver Alliance and the Rutgers Center for State Health Policy.

### *Supportive Care Needs of Americans: A Major Issue for Women as Both Recipients and Providers of Such Care.*

[http://www.ncbi.nlm.nih.gov/pubmed/17194871?ordinalpos=2&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed\\_ResultsPanel.Pubmed\\_RVDocSum](http://www.ncbi.nlm.nih.gov/pubmed/17194871?ordinalpos=2&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum)

This editorial defines the terms of caregiver and care recipients. In addition, the paper describes how caregiving is a major issue for women as both caregivers and care recipients.

### Reference:

McGuire LC, Anderson LA, Talley RC, Crews JE. Supportive care needs of Americans: A major issue for women as both recipients and providers of such care. *Journal of Women's Health* 2007;16(6):784-789.

### *The Development and Future of Workplace Eldercare*

By: Donna Wagner, Ph.D., Towson University

Published in 2000, this paper outlines current and future social trends affecting families and work, the historical development of workplace responses to caregiving employees, and the changes needed in the future in order to ensure that working Americans can meet their familial responsibilities while remaining productive contributors to the nation's economy.



History of  
Eldercare.pdf

### *The MetLife Study of Sons at Work: Balancing Employment and Eldercare*

Published in 2003, this report examines how caregiving situations are different for employed men and women and considers how gender makes a difference in balancing work and family. The findings are from a National Study by the National Alliance for Caregiving and the Center for Productive Aging at Towson University.



Sons at Work.pdf

### United States Department of Agriculture-Cooperative Extension System

*The Cooperative Extension System, also known as the Extension Service of the United States Department of Agriculture USDA, is the largest non-formal educational program in the world and is implemented across the United States to help people use research-based knowledge to improve their lives. The service is provided by the state's designated land-grant universities. In most states the educational offerings are in the areas of agriculture and food, home and family, the environment, community economic development, and youth and 4-H. The Cooperative State Research, Education, and Extension Service (CSREES) USDA administers funding for Smith Lever Act services in cooperation with state and county governments and land-grant universities.*

*The Cooperative Extension System is uniquely positioned to reach out to caregivers and their families-to inform and educate them about the myriad issues, challenges, and opportunities related to population aging. Current work in this area focuses on research, education, and outreach to individuals, families, and communities preparing for or experiencing the impact of population aging and associated transitions in the family life course. Most notably, the system provides educational information and resources to address caregiving needs from a multidisciplinary perspective, utilizing expertise in such areas as nutrition, financial security, health, and housing to address family caregiving and related aging issues. The Cooperative Extension Systems offers many educational resources for caregivers:*

## *eXtension*

[www.extension.org](http://www.extension.org)

This is an educational partnership of more than 70 universities to help improve life every day with access to objective, research-based information and educational opportunities. Currently in development, the site has already launched several Communities of Practice including the Family Caregiving Community of Practice that was launched in February, 2008. On the Family Caregiving Community of Practice website, there is access to rural caregiving experts. The Personal Finance Community of Practice also provides valuable information for caregivers and families <http://www.extension.org/personal+finance>

Additional resources available through eXtension include:

1. Rate your risk of cardiovascular disease: [www.ces.ncsu.edu/hhb/index.htm](http://www.ces.ncsu.edu/hhb/index.htm)
2. Support for Caregivers: <http://www.umext.maine.edu/onlinepubs/htmpubs/4206.htm>
3. Medication Misuse: <http://ohioline.osu.edu/ss-fact/0128.html>
4. Hiring and Working Successfully with In-Home Care Providers:  
<http://extension.oregonstate.edu/catalog/pdf/pnw/pnw547.pdf>

In collaboration with CSREES, cooperative extension system faculty has contributed information and resources to the development of the [2006-2007 Cooperative Extension System Resources, Contacts, and Collaborations: Aging Issues](http://www.csrees.usda.gov/nea/family/res/family_res_aging.html), with resources and contacts on aging issues organized by state. This e-publication includes the name and contact information for each of the partner institutions, as well as more detailed contact information for the heads of the aging education programs. Where the states have specific extension or other programs related to aging issues, more information describing the program is included. Originally developed in 2004, the resource will be updated yearly in June.

[http://www.csrees.usda.gov/nea/family/res/family\\_res\\_aging.html](http://www.csrees.usda.gov/nea/family/res/family_res_aging.html)

## University of Pittsburgh – University Center for Social and Urban Research

*The University Center for Social and Urban Research (UCSUR) was established by the University of Pittsburgh in 1972 to serve as a resource for researchers and educators interested in the basic and applied social and behavioral sciences.*

*Richard Schulz - Downloadable Published Articles by Date*

<http://www.ucsur.pitt.edu/PublishedArticles.htm>

This website contains a list of articles authored by Richard Schulz that can be downloaded.

## U.S. Administration on Aging (AoA)

*National Family Caregiver Support Program (NFCSP) Fact Sheets*

<http://www.aoa.gov/>

NFCSP develops fact sheets on topics of interest to caregivers and professionals.

*Workplace Programs for Family Caregivers: Good Business and Good Practice*

By: Donna L. Wagner, Ph.D.

Published in 2003 by the Family Caregiver Alliance, this monograph explores the balance between working and providing care through the presentation of case studies and research data. It discusses the historical development of workplace programs, models of workplace programs, and issues associated with the design of effective workplace caregiver programs.



2003\_workplace\_pro  
grams.pdf

### *Working Caregivers: Issues, Challenges, and Opportunities for the Aging Network*

By: Margaret Neal, Ph.D, Portland State University and Donna Wagner, Ph.D., Towson University

This paper provides an overview of the issues associated with working caregivers. It examines the social and demographic trends influencing the growth of this group, their characteristics and their contributions to elders and the consequences of caregiving for caregivers and their work. The paper details the potential role of the aging network in better supporting working caregivers, including best practices and other possible strategies.



Working Caregivers  
Issues and Challenge

## **Extra Help - Social Security Administration**

### Social Security Administration

*The mission of the Social Security Administration is to advance the economic security of the Nation's people through compassionate and vigilant leadership in shaping and managing America's Social Security program.*

### Extra Help Program

<http://www.ssa.gov/legislation/medi-mailing.html>

The Social Security Administration launched a new strategy to inform relatives and caregivers of low-income Medicare beneficiaries about the “extra help” available to assist them with the cost of the Prescription Drug Program.

## **Grant Programs**

### Aging and Disability Resource Centers (ADRC)

<http://www.aoa.gov/>

The Aging and Disability Resource Center (ADRC) Grant Program, a cooperative effort of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS), was developed to assist states in their efforts to create a single, coordinated system of information and access for all persons seeking long term support to minimize confusion, enhance individual choice, and support informed decision-making. Since 2003 43 states have received ADRC initiative grants.

### University of Alabama – Center for Mental Health and Aging

*The mission of The University of Alabama's Center for Mental Health and Aging (CMHA) is to develop new knowledge, test new interventions, and disseminate information related to mental health and aging. Through applied interdisciplinary research, the CMHA promotes improved quality of life for older adults. The CMHA has four focus areas: Elder Caregiving, Mental Health of Rural Elders, Quality of Care in Institutional Settings, and Palliative Care and End-of-Life Issues.*

*The Alabama REACH Demonstration Project - Caregiver Notebook -*

<http://www.cmha.ua.edu/CaregiverNotebook.pdf>

The state of Alabama received a grant from the Alzheimer's Disease Demonstration Grants to States program at the U.S. Administration on Aging to implement a 3-year program to improve direct services available to family caregivers by applying the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program. REACH is an evidence-based program funded by the National Institute on Aging, which includes in-home social and behavioral interventions that promote skill building. The Caregiver Notebook was a resource given to caregivers participating in the demonstration project.

*The Alabama REACH Demonstration Project – Resources for Enhancing Alzheimer's Caregivers Health: Case Worker Trainer Manual -*

<http://www.cmha.ua.edu/Case%20Worker%20Training%20Manual.pdf>

This Case Worker Training Manual was also used in Alabama's implementation of REACH as part of its grant from the U.S. Administration on Aging. This training session was designed to provide case workers with a comprehensive orientation to the practical interventions that have been found to be highly effective in the REACH studies.

### **Long Term Care**

*Own Your Future Website*

[http://www.longtermcare.gov/LTC/Main\\_Site/Planning\\_LTC/Campaign/index.aspx](http://www.longtermcare.gov/LTC/Main_Site/Planning_LTC/Campaign/index.aspx)

The Own Your Future Campaign is a project, started in January 2005, to increase consumer awareness about, and planning ahead for, long-term care. The project's core activities are state based direct mail campaigns supported by each participating state's Governor, and targeted to households with members between the ages of 45 to 70. Campaign materials include a Long-Term Care Planning Kit and state specific information and resources.

### **Medicare & Medicaid**

*The mission of the Centers for Medicare & Medicaid Services (CMS) is to ensure effective, up-to-date health care coverage and to promote quality care for beneficiaries, which will be accomplished by continuing to transform and modernize America's health care system.*

*Activities and Accomplishments of the Family to Family Health Care Information and Education Center Grantees*

<http://www.hcbs.org/files/91/4525/FTFPaper.pdf>

This paper is one in a series addressing major topic areas in the Systems Change for Community Living Grants Program. It describes the activities of 19 Grantees who received grant funding in fiscal years 2003 and 2004 CMS, and six Grantees funded in fiscal year 2002 by the Maternal and Child Health Bureau (MCHB)/Health Resources and Services Administration (HRSA). The purpose of the grants is to support the development of Family to Family Health Information Centers to assist families of children with special health care needs to obtain the wide range of services and supports they need. This paper describes grant activities, implementation challenges, and accomplishments. Its primary purpose is to provide information that states and stakeholders will find useful when planning or implementing similar initiatives.



### CMS Caregiver Partnerships

[http://www.cms.hhs.gov/Partnerships/25\\_CaregiverInitiative.asp#TopOfPage](http://www.cms.hhs.gov/Partnerships/25_CaregiverInitiative.asp#TopOfPage)

The Centers for Medicare & Medicaid Services (CMS) is launching an initiative this fall to begin a conversation with people who provide care for a loved one, friend or neighbor. The *Ask Medicare* initiative will provide information, tools and materials to assist the caregiver and their loved ones in making informed healthcare decisions.

### Innovative Strategies for Strengthening Family to Family Health Information and Education Centers

[http://www.hcbs.org/files/96/4754/F2F\\_PromPrac.pdf](http://www.hcbs.org/files/96/4754/F2F_PromPrac.pdf)

Following a brief overview of the Family to Family Centers are examples of grantees' implemented strategies to strengthen their Center, grouped by theme. Additional information and background on these practices was also obtained by reviewing grantees' Web sites and their annual grant reports. After each example, contact information is included so readers may easily learn more about particular practices.

### Medicare Publications

<http://www.medicare.gov/Publications>

CMS develops a wide range of publications on Medicare and other related topics, including:

#### Medicare Basics: A Guide for Caregivers

<http://www.medicare.gov/Publications/Pubs/pdf/11034.pdf>

Medicare Basics highlights eight decision points related to the health or overall well-being of an older person. For each of these decision points, you'll find basic information about Medicare and suggestions on finding more detailed information.

#### State Health Insurance Assistance Program (SHIP)

<http://www.medicare.gov/contacts/Static/SHIPs.asp?dest=NAV%7CHome%7CRelatedWebsites%7CSHIPs>

The State Health Insurance Assistance Program, or SHIP, is a national program available in every state that offers free one-on-one counseling and assistance (over the telephone or in-person) to people with Medicare and their caregivers.

#### When Employees Become Caregivers: A Manager's Workbook

<http://www.medicare.gov/Publications/Pubs/pdf/11035.pdf>

A Manager's Workbook guides employers in how to make eldercare and Medicare information available to caregiving employees at little or no cost.

\*Please note, the first page is the order form to send to AARP to request hardcopies

### MyMedicare.gov

<http://www.MyMedicare.gov>

Medicare's secure online service for accessing personal Medicare information. People with Medicare and their caregivers can use this website to track the individual's health care claims, eligibility information, preventives services used, and keep the individual's Medicare information in one convenient place.



### The Official Medicare Website for Consumers

<http://www.medicare.gov>

The medicare.gov website provides information and tools to inform consumers and assist caregivers in helping a loved one with their Medicare health benefits and choices. Don't forget Medicare's open enrollment is November 15 to December 31 every year. Go to [www.medicare.gov](http://www.medicare.gov) on the web to:

- See what Medicare plans are in your area.
- Find doctors who participate in Medicare.
- See what Medicare covers, including preventive services.
- Get Medicare appeals information and forms.
- Get information on the quality of care provided by nursing homes, hospitals, home health agencies, plans, and dialysis facilities.
- Look up helpful telephone numbers for your area.
- View Medicare publications.

## **State & Local Resources**

### Health Resources and Services Administration (HRSA)

*The Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services, is the primary Federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable. HRSA provides national leadership, program resources and services needed to improve access to culturally competent, quality health care.*

Family-To-Family Health Information Centers <http://www.familyvoices.org/projects/f2f.php> (website)

[http://www.familyvoices.org/pub/general/F2FHICs\\_HelpingFamilies.pdf](http://www.familyvoices.org/pub/general/F2FHICs_HelpingFamilies.pdf) (fact sheet)

Family-To-Family Health Information Centers are state-based, family-run centers providing technical assistance and parent support to families of children with special health care needs. They develop partnerships with those organizations serving these children and their families in order to assist families get community based resources and monitor the issues families have with services, financing and agencies. These centers have been funded by MCHB and the Centers for Medicare and Medicaid.

### *Eldercare Locator*

<http://www.eldercare.gov/>

The Eldercare Locator is a public service of the U.S. Administration on Aging and is the first step to finding resources for older adults in any U.S. community. The service links those who need assistance with state and local area agencies on aging and community-based organizations that serve older adults and their caregivers.

St. Andrew's Resources for Seniors (STARS) is a faith-based, non-profit organization founded by the Diocese of the Missouri-Protestant Episcopal Church and the Presbytery of Giddings-Lovejoy Presbyterian Church. STARS' efforts and expertise are bringing retirement living options, lifestyle security, enhanced well-being and health, and independence to thousands of seniors.

*St. Andrews Resources for Seniors – The Caring Workplace*  
<http://www.standrews1.com/caringworkplace/index.html>

The Caring Workplace is a resource for working caregivers. It was created because we understand how dealing with a loved one's needs while working can affect your concentration and work productivity. This is a model program funded by the Administration of Aging that provided eldercare management at twelve local businesses for their employees who are caregivers.

Corporate Eldercare Implementation Guide (PDF):  
<http://www.standrews1.com/caringworkplace/Corporate%20ElderCare%20Implementation%20Guide.doc.pdf>

## **Veterans Support**

### **Department of Veterans Affairs**

The Department of Veterans Affairs is the federal agency dedicated to meeting the needs of veterans of their families through providing excellence in patient care, veterans' benefits, and customer satisfaction.

### *Caregiver Assistance Pilot Programs*

<http://www1.va.gov/opa/pressrel/pressrelease.cfm?id=1428>

The VA announced on December 6, 2007 that it will provide nearly \$4.7 million for “caregiver assistance pilot programs” to expand and improve health care education and provide needed training and resources for caregivers who assist disabled and aging veterans in their homes.

### *Clinical Programs & Initiatives*

<http://www1.va.gov/health/clinical.html>

This website lists VA clinical programs and initiatives that support veterans and their families.