

“SUPPORTING RURAL FAMILY CAREGIVERS” Satellite Broadcast Resource List

The “Supporting Rural Family Caregivers” Satellite Broadcast is presented by the New Freedom Initiative (NFI) Subcommittee on Caregiving in partnership with the Centers for Medicare & Medicaid Services. NFI is a government-wide effort directed at eliminating the barriers that prevent people with disabilities from participating in full community life. People with disabilities and older adults – and the people who care for them – can all benefit from being engaged in community life.

Through this broadcast, the NFI Subcommittee on Caregiving hopes to initiate discussion of the challenges faced by rural family caregivers, offer resources and information, and present potential solutions. This Resource List contains links to electronic resources for both caregivers and professionals developed by a variety of organizations including federal, national, state, and local agencies.

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New Freedom Initiative

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

President Bush announced the New Freedom Initiative on February 1, 2001, 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 Subcommittee on Caregiving

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.

AARP

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.

Caring for Those You Care About

“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.

Prepare to Care

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.

Economic Value of Family Caregiving

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

Tune into your local PBS station on April 2 for a special primetime program, Caring for your Parents, which is an eye-opening two hour broadcast event that draws much needed attention to the realities of caring for older parents (check your local listing). As a complement to the PBS special, a newly updated AARP book titled ***Caring for Your Parents, The Complete Family Guide, Practical Advice You Can Trust From the Experts at AARP***, by AARP Publications Editor-in Chief Hugh Delehanty and AARP's Livable Communities Strategy Director Elinor Ginzler, with foreword by Mary Pipher will be released April 1, 2008. The updated edition will be available at a 35% discount at: www.aarp.org/books.

Administration on Aging

www.aoa.gov

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.

Aging and Disability Resource Centers (ADRC)

http://www.aoa.gov/prof/aging_dis/aging_dis.asp

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.

Eldercare Locator

<http://www.eldercare.gov/> or 1-800-677-1116

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.

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

<http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp>

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. Resources include:

- [National Family Caregiver Support Program State Contacts](#) - this document will link you to NFCSP Project Directors in each state.
- [National Family Caregiver Support Program \(NFCSP\) State Websites](#) - this document will link you to NFCSP websites in each state.
- [National Family Caregiver Support Program \(NFCSP\) Fact Sheets](#) - NFCSP develops fact sheets on topics of interest to caregivers and professionals.

Native American Caregiver Support Program (NACSP)

<http://www.aoa.gov/prof/aoaprogram/caregiver/overview/fact.asp>

The Older Americans Act Amendments in 2000 also created the Native American Caregiver Support Program (NACSP). The above webpage contains several American Indian and Alaska Native-specific fact sheets. An additional resource on Native American elders is:

- [Conducting Local Assessments: Locating the Needs of Elders](#) - the purpose of this study is to compare Native American elders to the general U.S. population to determine the extent of existing social and health differences.

AoA's 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. Resources include:

- [Frontier Workshop](#) - the Technical Assistance Center of AoA's ADDGS National Resource Center conducted a Frontier Workshop in Cheyenne, Wyoming. The Workshop was designed to provide ADDGS grantees and project partners from frontier states with an opportunity to discuss issues of mutual concern and learn about innovative ways to improve service delivery to people with Alzheimer's disease and their families in frontier communities.
- [Case Study on Colorado's ADDGS Grant](#) – this case study describes Colorado's 2002-2005 ADDGS Grants. The goal of this grant was to increase access to supportive

services in rural areas of the state, with special sensitivity to the bilingual Hispanic population.

Seniors Benefit from Transportation Partnerships: Promising Practices from the Aging Network
<http://www.aoa.gov/prof/transportation/transportation.asp>

The 14 communities showcased in this report provide valuable lessons for the aging network: they show how better transportation services for seniors resulted when various transportation programs were successfully coordinated. Communities where the aging network played a vital role in establishing and maintaining coordinated transportation services are emphasized, as are communities whose coordination efforts have not been fully documented in other reports. The communities were selected by consulting experts and from previous research. All of these communities demonstrate replicable coordination strategies with significant measurable benefits.

Alzheimer's Association

www.alz.org

The mission of the Alzheimer's Association is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Online resources include:

Carefinder

<http://www.alz.org/carefinder/index.asp> - Carefinder is an interactive tool that recommends options and lists questions to ask when screening care providers.

Contact Center

http://www.alz.org/we_can_help_24_7_helpline.asp

The Administration on Aging funds a National Alzheimer's Contact Center, operated by the Alzheimer's Association, which offers information and referral services 24 hours a day, 7 days a week, 365 days a year. The Contact Center focuses on reaching underserved populations. It has a translation service that is capable of providing interpretation for 140 languages. To reach the Contact Center anytime of day, call 1-800-272-3900.

Lotsa Helping Hands

<http://alzheimers.lotsahelpinghands.com> - Lotsa Helping Hands is a simple, immediate way for friends, family, colleagues, and neighbors to assist loved ones in need. It's an easy-to-use, private group calendar, specifically designed for organizing helpers, where everyone can pitch in with meals delivery, rides, and other tasks necessary for life to run smoothly during times of medical crisis, end-of-life caring, or family caregiver exhaustion. It's also a place to keep these 'circles of community' informed with status updates, photo galleries, message boards, and more.

Message Boards

http://www.alz.org/living_with_alzheimers_message_boards_lwa.asp - Specific Message Boards on the Alzheimer's Association website include: Alzheimer's under age 65, Caregiver's Forum, and Caregivers Who Have Lost their Loved Ones.

Caregiver.com

<http://www.caregiver.com>

Caregiver Media Group provides information, support and guidance for family and professional caregivers. Founded in 1995, they produce Today's Caregiver magazine, the first national magazine dedicated to caregivers, the "Sharing Wisdom Caregivers Conferences", and the caregiver.com website.

Weekly Newsletter

http://www.caregiver.com/caregiver_newsletter/index.htm

Weekly newsletter that contains information on a variety of caregiving topics.

Centers for Medicare & Medicaid Services

The Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services, is responsible for ensuring effective, up-to-date health care coverage and promoting quality care for approximately 90 million beneficiaries in the Medicare, Medicaid, and State Children's Health Insurance Programs.

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. Go to www.medicare.gov on the web to do the following:

- 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

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.

Medicare Publications

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

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

- what Medicare covers
- Programs to help people with Medicare save money
- Medicare prescription drug coverage, Medicare health plans, and Medigap
- Choosing a nursing home, home health agency, or dialysis facility
- Medicare's preventive services

In addition, CMS has developed two publications written specifically for caregivers:

- *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.
- *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

State Health Insurance Assistance Program (SHIP)

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. To find the SHIP telephone number for your state, visit www.medicare.gov on the web. Under "Search Tools," select "Find Helpful Phone Numbers and Websites."

CMS Caregiver Partnerships and Caregiver Workgroup

http://www.cms.hhs.gov/Partnerships/12_Caregiver.asp#TopOfPage

CMS formed a Caregivers Workgroup in 1999, composed of caregiver organizations, beneficiary advocacy groups, providers, insurers, employers, and other organizations with an interest in care giving. This group meets quarterly and discusses how Medicare information can better be communicated to this population and what the members of this group can do to make that happen.

DHHS Office of Rural Health Policy

www.ruralhealth.hrsa.gov.

The Office of Rural Health Policy promotes better health care service in rural America. Established in 1987, the Office is located in the Health Resources and Services Administration. Congress charged the Office with informing and advising the Department of Health and Human Services on matters affecting rural hospitals, and health care, coordinating activities within the Department that relate to rural health care, and maintaining a national information clearinghouse.

Rural Healthy People 2010

<http://srph.tamhsc.edu/centers/rhp2010/>

"Healthy People 2010: A Companion Document for Rural Areas," is a project funded with grant support from the Federal Office of Rural Health Policy. The purpose of this research project is to develop a companion document to the Department of Health and Human Services (DHHS) [Healthy People 2010](#) objectives, a document addressing rural priorities.

Easter Seals

Easter Seals has been helping individuals with disabilities and special needs, and their families, live better lives for more than 85 years. From child development centers to physical rehabilitation and job training for people with disabilities, Easter Seals offers a variety of services to help people with disabilities address life's challenges and achieve personal goals. Easter Seals website contains a specific section on support for caregivers:

http://www.easterseals.com/site/PageServer?pagename=ntl_ads_caregiver. Additional resources include:

Caregiving in Rural America:

http://www.easterseals.com/site/PageServer?pagename=OPA_ruralcaregiving&s_scr=shortcuturi&s_subsrc=ruralcaregiving

The National Alliance for Caregiving and Easter Seals have produced this report to bring to light and support the demand to address the ever-increasing numbers and unmet needs of rural caregivers.

Easter Seals Project ACTION

http://projectaction.easterseals.com/site/PageServer?pagename=ESPA_homepage

Funded through a cooperative agreement with the U.S. Department of Transportation, Federal Transit Administration, Easter Seals Project ACTION promotes cooperation between the transportation industry and the disability community to increase mobility for people with disabilities under the ADA and beyond. This training and technical assistance center offers numerous resources and activities to make the ADA work for everyone, everyday to achieve Accessible Community Transportation In Our Nation (ACTION). Project ACTION has a number of training events, clearinghouse materials, an 800 information line Monday-Friday 9:00 a.m.- 5:00 p.m. (Eastern Time) at (800) 659-6428 (voice), newsletters. Additionally, to help put knowledge into action, Project ACTION staff teaches individuals and communities how to build, use, and strengthen accessible transportation through a number of training initiatives.

National Center on Senior Transportation

www.seniortransportation.net

The National Center on Senior Transportation is a training and technical assistance center administered by Easter Seals, Inc. in partnership with the National Association of Area Agencies on Aging and is dedicated to increasing transportation options for older adults to enhance their ability to live more independently within their communities throughout the United States. Its goals are to achieve this mission through the development, collection and distribution of information and resources for use by communities, transportation providers, state and local governments, aging and human service providers, and older adults and their caregivers. Technical assistance, research toward solutions, strategic communications and building partnerships among stakeholders are additional functions of the center. The Center features a number of useful publications and initiatives including:

- United We Ride's *Framework for Action: Building the Fully Coordinated Transportation System* – http://www.unitedweride.gov/1_81_ENG_HTML.htm - a self-assessment tool for communities and states that can be used for coordinated transportation strategies and efficient transportation solutions.
- Transportation Solutions for Caregivers: A Starting Point
http://www.easterseals.com/site/PageServer?pagename=ntl_tsc_toolkit - this toolkit provides information on: communication, sensitivity, preventing agitation, dealing with agitation, transportation options, and providing physical assistance.

Georgia Department of Human Resources, Division of Aging Services

<http://www.aging.dhr.georgia.gov/portal/site/DHR-DAS/>

The Georgia Department of Human Resources, Division of Aging Services administers a statewide system of services for senior citizens, their families and caregivers. The Division works with other aging agencies and organizations to effectively and efficiently respond to the

needs of elderly Georgians. To view the Division's resources click on "Publications" on the left side of the screen. Rural caregiving related products include:

- Mobile Day Care Video
- Self Directed Care Fact Sheet
- Self Directed Care Guidebook

Minnesota Board on Aging

www.minnesotahelp.info

MinnesotaHelp.info is an online directory of services designed to help people in Minnesota identify resources such as human services, information and referral, financial assistance, and other forms of aid and assistance within Minnesota. It is especially rich in resource information for seniors and their caregivers; people with disabilities and their caregivers; parents and families; and low income people. In 2007, MinnesotaHelp.info received a technology award from the National Alliance for Caregiving and the MetLife Foundation.

National Rural Health Association

www.NRHArural.org

The NRHA is a national nonprofit membership organization with more than 18,000 members that provides leadership on rural health issues. The association's mission is to improve the health and wellbeing of rural Americans and to provide leadership on rural health issues through advocacy, communications, education, research and leadership. Current publications include:

- [Practical Tips And Information Resources For Developing Collaborative Relationships Between Rural Community Health Centers \(CHCs\) and Rural Hospitals](#)
- [Telehealth Technical Assistance Manual](#)
- [Rural Health Disparities Collaboratives: Benefits, Barriers and Adaptations for the Future](#)
- [Contracting with the Veterans Administration as a Community-Based Outpatient Clinic](#)
- ["Setting the PACE for Rural Elder Care - A Framework for Action"](#)
- [Providing Hospice and Palliative Care in Rural and Frontier Areas](#)

Purdue University's Breaking New Ground Resource Center

<http://abe.www.ecn.purdue.edu/ABE/Extension/BNG/Outreach%20Program/outreach.html>

Since its start in 1979, The Breaking New Ground Resource Center in Purdue's Department of Agricultural and Biological Engineering has become an internationally recognized source for information and resources on rehabilitation technology for persons working in agriculture.

On this website you'll find links to:

Caregiver Resources Information

<http://cobweb.ecn.purdue.edu/~agenthtml/ABE/Extension/BNG/Resource%20Center/caregiver.html>

This webpage features a large collection of links to helpful sites for caregivers on topics including a "Guide for Caregivers of Farmers and Ranchers with Disabilities" and information on "Barn Builders," a peer support network of farmers and ranchers with disabilities.

The Rural Caregivers Website

www.ruralcare.info

This website is designed to help bridge the information gap and assist in creating a web support community for rural caregivers.

Rural Assistance Center

www.raconline.org

A product of the U.S. Department of Health and Human Services' Rural Initiative, the Rural Assistance Center (RAC) was established in December 2002 as a rural health and human services "information portal." RAC helps rural communities and other rural stakeholders access the full range of available programs, funding, and research that can enable them to provide quality health and human services to rural residents.

Senior Services of Albany

Telephone Caregiver Support Group Project

<http://www.seniorservicesofalbany.com/AOA.cfm>

The Telephone Support Group project began in 2002 as a three-year, Administration on Aging funded program. The goals of the project include reaching isolated family caregivers not being served by in-person groups and evaluating the effectiveness of support groups conducted over the telephone. This website is intended to disseminate information about this project, the model used to lead the Telephone Support Groups, the benefits of this model and mode of delivery, and the outcomes of the research into the effectiveness of the dozen groups conducted under this project. Additional resources on this website include:

- Leading a Telephone Caregiver Support Group: A Manual for a Model Psychoeducational Program:
<http://www.seniorservicesofalbany.com/pdf/TSG%20Manual%201.1.pdf>
- Telephone Support Program: Participant Workbook:
<http://www.seniorservicesofalbany.com/pdf/TSG%20Workbook%201.1.pdf>

University of New Hampshire, Carsey Institute

www.carseyinstitute.unh.edu .

The Carsey Institute sponsors independent, interdisciplinary research that documents trends and conditions in rural America, providing valuable information and analysis to policymakers, practitioners, the media, and the general public. The Institute has current reports demographics, population trends, and policy implications for rural areas.

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

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>.

AgrAbility Program

http://www.csrees.usda.gov/nea/ag_systems/in_focus/workforce_if_agrability.html

AgrAbility is a consumer-driven USDA-funded program that provides vital education, caregiving assistance, and support to farmers and ranchers with disabilities. Through the combined dedication and expertise of the Cooperative Extension System and nonprofit disability organizations, AgrAbility in partnership with organizations such as Easter Seals, helps thousands of determined individuals overcome the barriers to continuing their chosen professions in agriculture. Visit the <http://www.agrabilityproject.org/stateprojects.cfm> link and click on your state to see the resources available to you.

Cooperative Extension System Publication on Aging Issues

http://www.csrees.usda.gov/nea/family/pdfs/aging_resources.pdf

In collaboration with CSREES, 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.

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 kshannon@lhs.org at 503.413.6778 or Leslie Congleton lconglet@lhs.org at 503.413.7032.

Wisconsin Alliance for Family Caregiving

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

The Wisconsin Alliance for Family Caregiving is a statewide non-profit organization with the mission of providing education, support, and resource to professionals who work directly with family caregivers.

League of Experienced Caregivers

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.

Partners in Caregiving

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

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

Other Rural Caregiving Reports

Alzheimer's Caregiving in Rural Communities: Can Telehealth Help?

http://www.e-psychologist.org/index.html?mdl=exam/show_article.mdl&Material_ID=15.

The paper (via the webpage) above provides an overview of the challenges faced by rural family caregivers in obtaining educational and support services, including lack of resources and the stigma they confront in seeking psychological assistance. Second, the rationale for cognitive-behavioral (CB) intervention for caregivers of individuals with progressive dementia is provided, followed by a discussion of recent findings of telehealth-based CB outcome studies with this population. Finally, a new grant initiative is described that delivers telehealth-based CB classes and other services in rural settings.

Elder Caregiving in Rural Communities:

<http://www.centeronaging.uiowa.edu/archive/pubs/Elder%20Caregiving%20in%20Rural%20Communities.htm#conclusions>

This resource overviews elder caregiving in rural communities, rural caregiver population, literature on what supports rural caregivers, promising practices, and practice implications for the Aging Network.