

CAREGIVER RESOURCE DIRECTORY

Contents:

- Caregiver Organizations, Information, Advocacy, and Support Resources 2
- Caregiver-Specific Website s. 10
- Creating a Community of Support Online 19
- Caring for Elders 21
- End-of-Life Planning, Hospice, and Bereavement Information 25
- Health Insurance: Prescription Assistance Information 27
- Patient Advocacy Assistance and Programs 30
- Home Care Agencies. 31
- Adult Day, Assisted Living, Nursing Home, and Residential Care 32
- Medical Transport and Hospitality Housing. 35
- Respite Resources 36
- Training for Family Caregivers 39
- Government Agencies 40
- Veterans 41
- Mediation 43
- Disease Specific and Health Related Agencies and Website 44
- National Family Caregiver Support Program 54

Disclaimer: Information provided in this document was gathered via the Internet and last updated in 2015. Some information may have changed since this information was compiled.

Caregiver Organizations, Information, Advocacy and Support Resources

- **Alzheimers.gov**

Toll-free: 877-696-6775

Website: <http://www.alzheimers.gov>

A division of the U.S. Department of Health and Human Services, this website provides free information resource about Alzheimer's disease and related dementias. Here you can find links to authoritative, up-to-date information from agencies and organizations with expertise in these areas.

- **The Alzheimer's Project**

Website: <http://www.hbo.com/alzheimers/index.html>

While there is no cure for the disease, THE ALZHEIMER'S PROJECT shows there is now genuine reason to be optimistic about the future. Created by the award-winning team behind HBO's acclaimed "Addiction" project, this multi-platform series takes **aclose** look at groundbreaking discoveries made by the country's leading scientists, as well as the effects of this debilitating and fatal disease both on those with Alzheimer's and on their families.

- **The Brookdale Foundation Group – Relatives as Parents Program (RAPP)**

201-836-4602

Website: <http://www.brookdalefoundation.org/RAPP/rapp.html>

Established in 1996 in response to a growing understanding of the need for enhanced services and supports for grandparents raising grandchildren, The Brookdale Foundation Group established the Relatives as Parents Program (RAPP) to encourage and promote the creation or expansion of services for grandparents and other relatives who have taken on the responsibility of surrogate parenting due to the absence of the parents. Currently RAPP provides supportive services, primarily to relative caregivers caring for children outside the foster care system, through an extensive network of support groups across the country.

- **Children of Aging Parents (CAPS)**

Toll-free: 800-227-7294

Website: <http://www.caps4caregivers.org>

CAPS assists caregivers of the elderly with information and referrals, a network of support groups, and publications and programs that promote public awareness of the value and the needs of family caregivers.

- **eXtension**

402-472-7543

Website: http://www.extension.org/family_caregiving

This website was created by the United States Department of Agriculture (USDA), Cooperative Extension System. Here, caregivers and advocates can access a wide range of information and materials designed to help them learn about and provide supportive services to family and relative caregivers. Topics include disaster preparedness, military families, grandparents raising grandchildren, housing, and nutrition.

- **Elizabeth Dole Foundation**

202-266-7932

Website: <http://elizabethdolefoundation.org>

The Elizabeth Dole Foundation teams with individuals and organizations across the country to build a powerful national coalition to address the significant gaps in support. The military caregiver crisis facing our nation will require holistic support and a broad range of resources. Prominent leaders from the public, private, nonprofit, labor and faith communities are stepping forward to support America’s hidden heroes—our nation’s military and veteran caregivers.

- **Family Caregiver Alliance (FCA)**

Toll-free: 800-445-8106

Website: <http://www.caregiver.org>

e-mail: info@caregiver.org

FCA is the lead agency in California's system of Caregiver Resource Centers. FCA provides support and help to family caregivers and champions their cause through education, services, research and advocacy. Services are specific to California, although information can be accessed nationally.

- **Family Voices, Inc.**

Toll-free: 888-835-5669

Website: <http://www.familyvoices.org>

Family Voices offers information on healthcare policies relevant to special needs children in every state.

- **Freedom From Smoking Online**

Website: <http://www.ffsonline@easterseals.org> or <http://www.ffsonline.org>

Freedom From Smoking[®] Online, or FFS Online, is a program specifically designed for adults who want to quit smoking. It's an adaptation of the American Lung Association's gold standard, group clinic that has helped thousands of smokers to quit for good. FFS Online takes you through modules, each containing several lessons that you access through this protected website. These lessons include valuable information and most of them contain an assignment that you are to complete before moving on. The assignments reinforce the messages in each lesson and your commitment to quit.

- **Friends' Health Connection**

Toll-free: 800-483-7436

Website: <http://www.48friend.org>

Friends' Health Connection links persons with illness or disability and their family caregivers with others experiencing the same challenges.

- **Generations United**

202-289-3979

Website: <http://www.gu.org>

Generations United is the national membership organization dedicated to improving the lives of children, youth, and older people through intergenerational strategies, programs, and public policies. Generations United represents more than 100 national, state, and local organizations representing more than 70 million Americans. With its emphasis on public policy, advocacy and programming, Generations United has served as a resource for policymakers and the public on the economic, social, and personal imperatives of intergenerational cooperation.

- **Gilda's Club**

Gilda's Club offers a community based program of social, emotional and educational support for men, women, teens and children living with cancer along with their families and friends; search Internet for a Gilda's Club near you.

- **HealthMatters Program**

Website: <http://www.healthmattersprogram.org>

HealthMatters Program is a partnership between community and academia with a common aim to improve health of people with developmental disabilities (DD). Our goals are to develop and share tools for bidirectional health promotion research, service-learning, and training, support health promotion program development, implementation, and evaluation and disseminate and

integrate evidence-based health promotion services for people with DD.

- **Lutheran Social Services**

847-635-4600

Website: <http://www.lssi.org>

LSSI offers a full continuum of services to meet the changing needs of seniors. Services like home care and adult day services extend the time that seniors can remain independent in their homes. Other services like the RSVP Program enable seniors to give back to the community by volunteering for different nonprofits in their local communities. By caring for seniors, LSSI alleviates caretaker stress and enables seniors to live as independently and safely in the community as possible.

- **My Health Matters**

Website: http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

- **National Alliance for Caregiving**

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

Although not an organization that helps family caregivers directly, The National Alliance for Caregiving's Website helps family caregivers learn about information, videos, pamphlets, etc. that have been reviewed and approved as providing solid information.

- **National Care Planning Council**

Toll-free: 800-989-8137

Website: <http://www.longtermcarelink.net>

Resource for Eldercare, Senior Services and Care Planning; publish articles, books, and guides to help you learn how to meet the needs of seniors. The providers and services listed under "Senior Services" are here to help with any retirement or eldercare need. Learn how to receive additional income from VA Benefits to help pay for home care, assisted living, or nursing care.

Find companies and individual providers in your area who can help your family with senior care and long term care planning. Find books written by the NCPC to help you plan for and fund the final years of life or learn how to obtain government benefits.

- **National Family Caregivers Association**

Toll-free: 800-896-3650

Website: <http://www.thefamilycaregiver.org>

e-mail: info@thefamilycaregiver.org

CAN is a national nonprofit organization dedicated to empowering family caregivers to act on behalf of themselves and their loved ones, and to remove barriers to their health and wellbeing. CAN concentrates its efforts in three primary areas: education, building community, and advocacy. **For more information visit:** www.thefamilycaregiver.org.

- **National Task Group on Intellectual Disability and Dementia Practices**

Website: <https://www.aadmd.org/NTG>

The ‘NTG’ is a coalition of individuals and organizations working toward ensuring that the needs and interests of adults with intellectual and developmental disabilities who are affected by Alzheimer’s disease and related dementia – as well as their families and friends – are taken into account as part of the National Plan to Address Alzheimer’s Disease. Members are families, association and organization representatives, practitioners, academics, and others who contribute time and effort to its activities. The NTG is supported by the American Academy of Developmental Medicine and Dentistry and the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago and other partners, such as the Center on Excellence in Aging at the University at Albany and the Gerontology Division of AAIDD.

- **Rosalynn Carter Institute for Caregiving (RCI)**

229-928-1234

Website: <http://www.rosalynncarter.org>

The Rosalynn Carter Institute for Caregiving establishes local, state and national partnerships committed to building quality, long-term, home and community-based services. We believe this begins with providing caregivers with effective supports to promote caregiver health, skills and resilience. We also believe strongly in the need to provide greater recognition for professional and family caregivers. We focus on helping caregivers coping with chronic illness and disability across the lifespan. RCI overall goal is to support caregivers – both family and professional- through efforts of advocacy, education, research, and service.

- **Sibling Leadership Network**

312-996-1002

Website: <http://www.siblingleadershipnetwork.org>

The mission of the Sibling Leadership Network is to provide siblings of individuals with disabilities the information, support and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.

- **Stroke Survivors Empowering Each Other (SSEEO)**

Toll-free: 888-988-8047

Website: <http://www.sseeo.org>

SSEEO is the first non-profit patient-supported stroke advocacy group in the nation. Founded in 2004 by stroke survivors, we have hundreds of members who are championing for survivors and their families in communities across Illinois. Through our newsletters, website, toll-free lunch and learn series we are now able to reach families in other states, as well as other countries. Originally sponsored by the American Heart/American Stroke Association, SSEEO is now an independent, 501(c)(3) organization run by those whose life has been affected by stroke.

- **Synapse House**

Toll-free: 877-932-1120

Website: <http://www.synapsehouse.org>

Synapse House is a nonprofit organization dedicated to providing long term support and services to those with acquired brain injury and the families that provide their care. We strive to use evidence based models of care to provide quality, cost effective services to meet the many needs of those with brain injury and stroke. **Mission:** To reconnect individuals with brain injuries or stroke back into life, the community, and the workplace through the use of productive activities in community-based programs that help maximize rehabilitation, and strengthen the ability to adapt and compensate.

- **U.S. Department of Health and Human Services**

Website: www.healthfinder.gov

A federal Web site designed to help people stay healthy. Healthfinder.gov features links to more than 6,000 government and nonprofit health information resources on hundreds of health topics including personalized health tools such as health calculators, activity and menu planners, recipes, and online checkups. In addition, the site offers tips for caregivers and health news. Information is provided in English and Spanish.

- **Well Spouse Association**

Toll-free: 800-838-0879

Website: <http://www.wellspouse.org>

e-mail: info@wellspouse.org

Well Spouse is a national membership organization that gives support to husbands, wives and partners of the chronically ill and/or disabled. Well Spouse has a network of support groups and also a newsletter for spouses.

Caregiver-Specific Websites and Tools

There are a variety of websites which offer information and support for family caregivers.

Websites with key information and support for family caregivers include:

- **AgingCare.com**

239-594-3235

Website: <http://www.agingcare.com/>

e-mail: editor@agingcare.com

AgingCare.com helps people caring for elderly parents find support, resources and information, as well as a place to connect with other caregivers. AgingCare.com has a comprehensive collection of articles, news, product information, as well as a team of elder care experts who answer the many tough questions caregivers have about caring for their loved ones. Most importantly, AgingCare.com provides a community in which caregivers can connect with others in similar situations, to share ideas and help each other through the tough times.

- **AGIS Network**

Toll-free: 866-511-9186

Website: <http://www.agis.com/>

e-mail: info@agis.com

AGIS.com provides education, support, expert advice, local resources and a vibrant community for caregivers and families of the elderly.

- **Allsup Medicare Advisor®**

Toll-free: 888-271-1173

Website: <http://www.allsup.com/nfca.aspx>

e-mail: medicarehelp@allsupinc.com

Allsup Medicare Advisor is a fee-based Medicare plan selection service helping Medicare eligible individuals, either alone or with their caregivers, to choose the Medicare option that best meets their needs. CAN Members are eligible to receive a 20% discount.

- **CareConnection.com**

Website: <http://www.careconnection.com>

CareConnection.com is Website devoted to family caregivers, with up-to-date health news, elder care specialists, experts, insurance help, and coping advice. The site, owned by HealthCentral.com, offers in-depth resources from trusted sources, interactive tools, and connections to leading experts and caregivers who share their experiences and inspiration.

- **CareCrossroads.org**

Website: <http://www.carecrossroads.org>

Care Crossroads is the Alzheimer's Foundation of America's dynamic, interactive community of care specifically designed to meet the educational, emotional, practical and other emerging needs of caregivers of individuals with Alzheimer's disease and related dementias. Using whichever communication type fits your convenience and comfort level, they invite you to meet, learn and connect with caregivers and professionals to ease your caregiving journey.

- **Caregiver.Com**

Toll-free: 800-829-2734

Website: <http://www.caregiver.com>

e-mail: info@caregiver.com

Caregiver.com produces *Today's Caregiver magazine*, the first national magazine dedicated to caregivers, the "Sharing Wisdom Caregivers Conferences", and Website which includes topic specific newsletters and online discussion lists.

- **Caregiver Action Network.com**

Website: <http://www.caregiveraction.org>

- **Caregiving.com**

Website: <http://www.caregiving.com>

A community of supportive individuals caring for family members and friends who have a chronic illness, disease or injury. We care for parents, grandparents, siblings, spouses, children and anyone we consider family.

- **Caregivinghelp.org**

773.381.6008

Website: www.CAREgivinghelp.org

Email: CAREgivinghelp@cje.net

CAREgivinghelp.org is free, interactive website featuring short video and text educational modules on a variety of caregiving topics, frequently asked questions that cover the different phases of caregiving, an online community monitored by a geriatric care specialist, exercises to help caregivers "take a moment" for themselves, and a comprehensive listing of resources.

- **Centers for Medicare & Medicaid Services (CMS)**

Website: <http://www.medicare.gov/caregivers>

Ask Medicare will help family caregivers access and use valuable healthcare information, services and resources. This new CMS initiative will feature a one-stop Web page for caregivers, providing easy access to useful information about Medicare and other essential resources to help with family caregiving including links to key partner organizations that assist caregivers and beneficiaries, and will present personal stories from caregivers in the community.

- **COPD – Online Support**

Website: <http://www.copd-support.com>

Online forums and chat rooms for people with COPD and their caregivers.

- **DailyStrength.com**

Website: www.dailystrength.org

Network of people sharing knowledge, experiences, and support.

- **Disability.gov**

Website: <http://www.disability.gov/>

A federal government website providing easy access to disability-related information and resources, Disability.gov has links to relevant programs and services offered by numerous government agencies. It is designed as a one-stop website where people with disabilities can easily find the resources they need to fully participate in the workforce and in their communities. Included is a state and local resources map, which makes it easy to locate disability-related information in specific parts of the country.

- **Elder Care and Information Resource Guide**

Website: <http://www.elderpages.com>

This website is sponsored by care managers, home care providers, elder law attorneys and home health professionals across the country. All are dedicated to supporting seniors to stay safe, healthy and independent. Each company has its own website with an e-library of articles that will help you as a family member, adjust to your changing role as a family caregiver. Many of these websites also include an online directory of local, state and national programs, and a monthly e-newsletter you can subscribe to for free. Services available in: California, Florida, Maine, Massachusetts, Michigan, New Hampshire, New York, North Carolina, Ohio, Pennsylvania, Tennessee, Texas, and Washington.

- **Family Caregiver Alliance (FCA)**

Toll-free: 800-445-8106

Website: <http://www.caregiver.org>

FCA is a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

- **HCV Support**

Website: <http://www.hcvsupport.org>

A message board for caregivers of people with Hepatitis C.

- **The Healing Project**

Email: amy@thehealingproject.org

Website: <http://www.thehealingproject.org>

The Healing Project is dedicated to providing support, education, resources, and help to those who face life-threatening and life-altering diseases and encourages those who have a personal story to share can submit an essay that will provide insight, hope, courage, and healing to those who may be newly diagnosed or living with the disease.

- **HelpGuide.org**

Website: <http://www.helpguide.org/articles/stress/caregiving-stress-and-burnout.htm>

Tips on how to regain balance in your life.

- **Home Instead - Caregiverstress**

Website: www.caregiverstress.com

While family caregiving is often very rewarding and a bonding experience, it can also be stressful and cause tension within families. Home Instead Senior Care provides this informative Website to help family caregivers find ways to cope with caregiver stress, in order to make their

role more rewarding. A caregiver who takes care of herself or himself - *body and mind* - will ultimately be a better caregiver to a loved one.

- **Homecare Agencies - Right at Home**

Website: www.rightathome.net

Right at Home is a national in-home care and assistance agency that provides your loved ones with the care and attention they deserve in the comfort of their own surroundings. Our local offices provide well-trained, insured and bonded caregivers for a variety of elder care services, and manage that care locally on your behalf. Whether you are seeking help with basic home maker services, personal care, or light skilled nursing, caregivers with Right at Home deliver quality care that can help your loved ones remain independent and fulfilled. Visit www.rightathome.net to learn more and to locate an office.

- **ITN Men’s Caregiver Support Group program**

Email: mlberg.caregiver.blog@gmail.com

Website: <http://mlberg.spaces.live.com/>

ITN (In Their Names) seeks to help men build their communication skills to become better caregivers. This is done by learning to share their stories with others, developing abilities to cope, making flexible and realistic plans, and gaining confidence as a caregiver. ITN was created as a step-by-step guide for men to develop a caregiver support group within their own communities.

- **Leeza’s Care Connection**

Toll-free: 1-888-OK-LEEZA, 1-888-655-3392

Website: <http://www.leezascareconnection.org>

Leeza’s Care Connection is a place for caregivers to “Summon their Strength” and call on their courage when a health crisis hits in their family. It is a place to go for support, to ask questions,

find resources and connect with other caregivers. A place where caregivers learn the importance of holding onto yourself while caring for someone you love.

- **National Caregivers Library**

Website: <http://www.caregiverslibrary.org>

The National Caregivers Library is an extensive library for caregivers. Find hundreds of articles, forms, checklists, and links to topic-specific external resources, organized by caregiver basics, caring for yourself, care facilities, end of life issues, long-distance housing, transportation, legal issues, etc.

- **National Family Caregivers Association (CAN)**

Toll-free: 800-896-3650

Website: <http://www.thefamilycaregiver.org>

CAN is a national nonprofit organization dedicated to empowering family caregivers to act on behalf of themselves and their loved ones, and to remove barriers to their health and wellbeing. CAN concentrates its efforts in three primary areas: education, building community, and advocacy. **For more information visit:** www.thefamilycaregiver.org.

- **The National Resource Directory**

Website: www.nationalresourcedirectory.org

Developed by the Departments of Defense, Labor and Veterans Affairs for wounded, ill and injured service members, veterans, their families and families of the fallen, and those who support them. The Directory provides over ten thousand services and resources available through governmental and non-governmental organizations to support recovery, rehabilitation and reintegration into the community.

- **New Health Partnerships**

Website: www.newhealthpartnerships.org

New Health Partnerships (NHP), a program of the Institute for Healthcare Improvement, is spreading collaborative self-management support, a system of care that promotes patient/family caregiver/provider partnerships to transform care for the chronically ill. The site offers valuable tools and resources that can be easily downloaded by patients, family caregivers, and their health care team.

- **Next Step in Care**

Website: <http://www.nextstepincare.org>

Offering a range of guides and checklists—most intended for family caregivers of persons with serious illness, with some specifically for health care providers—designed to make patients' transitions between care settings such as rehab to home or home to hospital smoother and safer.

- **ShareTheCaregiving – aka Share The Care**

Tel: 212-991-9688

Website: <http://www.sharethecare.org>

Email: info@sharethecare.org

ShareTheCaregiving Inc. is a grassroots organization dedicated to preventing "caregiver burnout by promoting and educating people about the benefits of group caregiving using the SHARE THE CARE™ model."

- **Strength for Caring**

Toll-free: 866-466-3458

Website: <http://www.strengthforcaring.com>

Strength for Caring is an online resource and community for family caregivers that helps family caregivers take care of their loved ones and themselves. Strength for Caring is part of The

Caregiver Initiative, created by Johnson & Johnson Consumer Products Company, Division of Johnson & Johnson Consumer Companies, Inc.

- **Video Caregiving**

Website: www.videocaregiving.org

A visual education tool for family caregivers of loved ones with Alzheimer’s Disease, strokes or other physical disabilities. The site features exclusive documentary-style videos, created by a team of award-winning film producers, which follow real life people as real life stories and issues unfold. Here caregivers find tools to better understand and deal with their situation, and let them know that they are neither isolated nor alone in their struggle.

Meet-Up

Website: <http://www.meetup.com>

Group-based site offering a broad range of like-minded groups.

Creating a Community of Support Online

- **CareCentral**

Website: <http://www.carecentral.com>

CareCentral is a personalized web service that allows users to create a private, secure online community for loved ones during significant health events. It is a free tool to update friends and family, organize and schedule offers to help, and encourage messages of hope, providing support when it is most needed.

- **CarePages**

Toll-free: 888-852-5521

Website: <http://www.carepages.com>

CarePages are free, private web pages that make it easy to reach out and receive messages of support and to stay connected to family, friends, co-workers and others who care about you and your loved one. The service is available to anyone caring for a loved one, but may be particularly helpful to those who have recently found themselves in a care giving role.

- **Caring Bridge**

Website: <http://www.caringbridge.org>

Create your own free, private website to keep family and friends informed. You can share updates and photos, and visitors can leave messages in your guestbook.

- **GrandmaSaysApp.com**

Website: <http://www.grandmasaysapp.com>

Free iPhone app for families to communicate with each other regarding their loved one, whether the loved one is at home, in an assisted living, or a nursing home. Includes health alerts, visit tracker, and task lists.

- **Lotsa Helping Hands**

Email: info@lotsahelpinghands.com

Website: <http://www.nfca.lotsahelpinghands.com>

Lotsa Helping Hands is a volunteer coordination service 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 a crisis.

- **Shirely BOARD: Where Caregivers Network**

Website: <http://www.shirleyboard.com>

A free, online community for caregivers of aging loved ones. You can create a private site and the you can store important caregiver information, keep an online journal of your experiences, share your updates with family, friends, and healthcare providers, and network with other caregivers.

Caring for Elders

Vital information and possible support services for the elderly can be obtained by contacting your local county office of senior services or elder affairs as well as your local social service department. Area adult daycare centers may also provide information on resources for the elderly in your area. These numbers can be located in the governmental pages of the phone book or through a web query.

- **AARP**

Toll-free: 800-424-3410

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

AARP supplies information about caregiving, long-term care and aging, including publications and audio-visual aids for caregivers.

- **AGIS Network**

Toll-free: 866-511-9186

Website: <http://www.agis.com/>

e-mail: info@agis.com

AGIS.com provides education, support, expert advice, local resources and a vibrant community for caregivers and families of the elderly.

- **ElderCare Forum**

Website: <http://www.ec-online.net>

An online forum for caregivers of the elderly.

- **Eldercare Locator**

National Association of Area Agencies on Aging

Toll-free: 800-677-1116

Website: <http://www.n4a.org> or <http://www.eldercare.gov>

Eldercare Locator provides referrals to Area Agencies on Aging via zip code locations. Family caregivers can also find information about many eldercare issues and services available in local communities.

- **Home Instead - 40/70 Rule**

Website: www.4070talk.com

What does a grown daughter say to her dad when he's hit a light pole with the car? How does an adult son ask his mom if she's taking her medications like she should? And how do siblings approach their parents about needing more help at home? These issues can challenge even the family where communication is free and open. Talking sooner is better than waiting until a crisis has occurred. That's what the "40-70 Rule" is all about. This advice is designed to help adult children and their aging parents deal with those sensitive topics that often make conversations difficult. The idea is that if you're 40, or your parents are 70, it's time to start talking about the issues of aging.

- **The National Association of Professional Geriatric Care Managers**

520-881-8008

Website: <http://www.caremanager.org>

Geriatric care managers (GCMs) are health care professionals, most often social workers, who help families in dealing with the problems and challenges associated with caring for the elderly. This national organization will refer family caregivers to their state chapters, which in turn can provide the names of GCMs in your area. This information is also available online.

- **The National Institute on Aging**

Toll-free: 800-222-2225

Website: <http://www.nia.nih.gov>

NIA, one of the 27 Institutes and Centers of NIH, leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life. NIA is the primary Federal agency supporting and conducting Alzheimer's disease research.

- **U.S. Administration on Aging**

202-619-0724

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

The Administration on Aging is the official federal agency dedicated to the delivery of supportive home and community-based services to older individuals and their caregivers. The AoA Website has a special section on family caregiving.

- **Veteran's Assistance**

- **Aid and Attendance and Housebound**

Website: http://www.benefits.va.gov/pension/aid_attendance_household.asp

Veterans and survivors who are eligible for a VA pension and require the **aid and attendance** of another person, or are **housebound**, may be eligible for additional monetary payment. These benefits are paid in **addition** to monthly pension, and they are not paid without eligibility to Pension.

Eligible Wartime Periods

Under current law, VA recognizes the following wartime periods to determine eligibility for VA Pension benefits:

- World War I (April 6, 1917 – November 11, 1918)
- World War II (December 7, 1941 – December 31, 1946)
- Korean conflict (June 27, 1950 – January 31, 1955)

- Vietnam era (February 28, 1961 – May 7, 1975 for Veterans who served in the Republic of Vietnam during that period; otherwise August 5, 1964 – May 7, 1975)
- Gulf War (August 2, 1990 – through a future date to be set by law or Presidential Proclamation)
- **American Veterans Aid**
Toll-free: 877-427-8065
Website: <http://www.americanveteransaid.com>

Wartime veterans and their surviving spouses, 65 years and older, may be entitled to a tax-free benefit called Aid and Attendance provided by the Department of Veteran Affairs. The Benefit is designed to provide financial aid to help offset the cost of long-term care for those who need assistance with the daily activities of living such as bathing, dressing, eating, toileting, and transferring. American Veterans Aid, a private company, is dedicated to helping war era veterans and their surviving spouses receive this Benefit which they so deserve. NOTE: American Veterans Aid is a private company and is not affiliated with the Veterans Administration or any government organization or agency.

- **Senior Helpers**
Toll-free: 877-844-9822
Website: <http://www.seniorhelpers.com/VeteranServices>

Senior Helpers® is helping senior veterans all over the U.S. understand how they can qualify and apply for the VA's Aid & Attendance Benefit, which pays seniors for the in-home senior care they need to live comfortably and safely. Veterans, spouses of veterans, and surviving spouses of veterans who are homebound or require the aid and attendance of another person can qualify for this payment if they meet certain criteria. Call Senior Helpers at 877-844-9822 to learn more.

End-of-Life Planning, Hospice, and Bereavement Information

Aging with Dignity

Toll-free: 888-5-WISHES 888-594-7437

Website: <http://www.agingwithdignity.org>

Aging with Dignity publishes the Five Wishes Living Will document, a very user-friendly and comprehensive document that meets legal requirements in 35 states.

- **Caring Connections**

Website: <http://www.caringinfo.org>

Caring Connections provides free brochures on end-of-life topics including advance care planning, caregiving, hospice and palliative care, pain, grief and loss and financial issues. Caring Connections also provides Advanced Directives for all states.

- **Easterseals – Enhancing Community-Based Options for End of Life Care**

Toll-free: 800-221-6827 (Easterseals' Adult and Senior Services program)

Website: <http://www.easterseals.com/our-programs/senior-services/enhancing-options-for-seniors.html>

Enhancing Community-Based Options for End of Life Care was funded by the [Retirement Research Foundation](#) to bridge the gap between adult day services and hospice and palliative care — two vital community based services. This initiative helps adult day services personnel and hospice and palliative care personnel across the country better understand each others' roles and integrate — from a clinical and programmatic standpoint — to better care for people at the end of their lives. The leadership, training, policy recommendations, tools and materials developed through this initiative pave the way for capacity building and collaboration among adult day and hospice organizations, allowing adult day service providers to offer more comprehensive services for people with life limiting illnesses and their families — promoting dignity and choice for millions of families across the country.

- **HospiceDirectory.org**

Toll-free: 800-868-5171

Website: <http://hospicedirectory.org/>

Online consumer database that lists hospices in North America and the U.S. All hospices are listed at no cost. It is a free service that assists families and individuals in locating a hospice within their community quickly. Also provides reliable information about hospice and end-of-life care to consumers.

- **Hospice Foundation of America**

Toll-free: 800-854-3402

Website: <http://www.hospicefoundation.org>

The National Hospice Foundation hosts an annual teleconference on issues of bereavement, and has publications on grief and bereavement.

- **The Compassionate Friends**

Toll-free: 877-969-0010

Website: <http://www.compassionatefriends.org>

This group offers telephone support and understanding to families who have lost a child. They maintain a resource library and have a national chapter network and newsletter.

- **U.S. Department of Health and Human Services**

National Clearing House for Long-Term Care Information

Website: <http://www.longtermcare.gov>

e-mail: aoainfo@aoa.hhs.gov

The National Clearinghouse for Long-Term Care Information provides information on planning and financing long-term care including planning for end of life care, and all major types of public and private financing to help cover long-term care costs.

Health Insurance: Prescription Assistance Information

Family caregivers can contact their county or state Department of Health and Human Services for financial programs which may provide assistance for acquiring health insurance and prescription medications. Other possible financial resources may include social service agencies such as Catholic Charities, the Association of Jewish Families, and Children's Agencies. Local chapters of voluntary health agencies may also offer financial support programs and/or information on how to apply for such programs.

- **AGIS Network**

Toll-free: 866-511-9186

Website: <http://www.agis.com/>

e-mail: info@agis.com

AGIS.com provides education, support, expert advice, local resources and a vibrant community for caregivers and families of the elderly.

- **Benefits Check-Up and Benefits Check-Up RX**

Websites: <http://www.benefitscheckup.org>

A service of the National Council on the Aging, Benefits Check-Up and Benefits Check-UP RX help people over the age of 55 find federal, state, and local public and private programs that may pay for some of their medical care and/or prescription costs.

- **HealthInsurance.com**

Toll-free: 800-942-9019

Website: <http://www.healthinsurance.com>

This website provides consumers and small businesses with quotes for health insurance and may help those who have lost their health insurance find an affordable alternative.

- **Medicare**

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

This is the official Website for the Centers for Medicare and Medicaid Services (CMS), the agency responsible for Medicare Rx. The toll-free number is 800/MEDICARE.

- **Medicare Rights Center**

Toll-free: 888-HMO-9050 888-466-9050

Website: <http://www.medicarerights.org>

This is an independent source of health care information and assistance for older and disabled Americans, their caregivers, and the professionals who serve them. Medicare Interactive (MI) is the one-stop source for information about health care rights, options and benefits and it is designed to help people find answers to all their Medicare questions. The website also has a list of phone numbers for each state's "State Health Insurance Assistance Program."

- **Medicare Rx Matters**

Website: <http://www.MedicareRxMatters.org>

Designed to help users make decisions about the new Medicare prescription drug plan, this site has three specific portals: one for family caregivers, one for people with Medicare, and one for professionals. The Website provides an overview, easy-to-understand steps, and information to assist users in making personal decisions about Medicare prescription drug coverage.

- **Medicine Program**

573-996-7300

Website: <http://www.themedicineprogram.com>

This program is for persons who do not have coverage either through insurance or government subsidies for outpatient prescription drugs and for those who cannot afford to purchase medications at retail prices.

- **RxCompare**

Email: info@maprx.info

Website: <http://www.maprx.info>

RxCompare™ is a free tool developed by Medicare Access for Patients-Rx (MAPRx) to help users determine if they need to enroll in a Medicare drug plan and, if they do, to systematically compare the drug plans where they live and select the best option for their prescription needs. RxCompare™ works in tandem with Medicare's on-line "Prescription Drug Plan Finder" and with information available from plans or 1-800-MEDICARE .

Patient Advocacy Assistance and Programs

- **Patient Advocate Foundation**

Toll-free: 800-532-5274

Website: <http://www.patientadvocate.org>

Patient Advocate Foundation serves as a liaison between patients and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters relating to a patient's condition.

Homecare Agencies

- **National Association for Home Care and Hospice**

202-547-7424

Website: <http://www.nahc.org>

This organization for home healthcare agency providers allows family caregivers to use the Internet to access a list of member agencies across the country.

- **Visiting Nurse Associations of America**

617-737-3200

Website: <http://www.vnaa.org>

e-mail: vnaa@vnaa.org

VNAA promotes community based home healthcare. Family caregivers can contact them to find their local VNA.

Adult Day, Assisted Living, Nursing Home, and Residential Care

- **A Place for Mom**

866-344-8005

Website: <http://www.aplaceformom.com>

- **Assisted Living Federation of America**

703-894-1805

Website: <http://www.alfa.org>

The Assisted Living Federation of America (ALFA) is the largest national association exclusively dedicated to professionally-managed, resident-centered senior living communities and the seniors and families they serve. Since 1990, ALFA has advocated for choice, accessibility, independence, dignity, and quality of life for all seniors. ALFA's programs promote business and operational excellence through education, research, publications, professional networking and online tools designed to foster innovation and entrepreneurship in the field of senior living.

- **Consumer Consortium on Assisted Living (CCAL)**

703-533-8121

Website: <http://www.ccal.org>

CCAL is a national consumer-focused organization that is dedicated to representing the needs of residents in assisted living facilities and educating consumers, professionals, and the general public about assisted living issues. Family caregivers can request the publication "Choosing an Assisted Living Facility: Strategies for Making the Right Decision," which provides helpful information and a concise checklist for those contemplating this next step.

- **iSeniorSolution.com**

Website: <http://www.iseniorsolutions.com>

Founded in 2012, iSeniorSolutions provides seniors and their families with the best experience possible when searching for Senior Living, Health Care or Funeral needs throughout the United States and Canada. iSeniorSolutions provide free access to thousands of leaders in the industry, as well as, provides information, tools, and resources most beneficial to today's senior.

- **National Adult Day Services Association**

Toll-free: 877-745-1440

Website: <http://www.nadsa.org>

NADSA advances the national development, recognition and use of adult day services. They provide a coordinated program of professional and compassionate supervised services for adults in a safe place outside the home during the day. In fact, family caregivers who use adult day services are at reduced risk of illness, according to recent research. Adult day centers serve as an emerging provider of transitional care and short-term rehabilitation following hospital discharge. As a preferred platform for chronic disease management, adult day centers are an interactive, safe and secure environment for participants requiring supervised daily care. While nearly half of all participants nationally have some level of dementia, other common chronic diseases among participants include chronic hypertension, physical disability, cardiovascular disease, diabetes, mental illness and developmental disability. Adult day services provide a reliable source of support, restore balance in times of crisis, and enhance overall quality of life for caregivers.

- **National Citizens' Coalition for Nursing Home Reform**

202-332-2275

Website: <http://www.nccnhr.org>

This organization serves as an information clearinghouse and offers referrals nationwide for help with concerns about long-term care facilities.

- **CAN Senior Housing Locator**

206-575-0728

Website: <http://www.snapforseniors.com/>

e-mail: info@snapforseniors.com

CAN Senior Housing Locator powered by SNAPforSeniors® is a current, comprehensive and objective resource of senior housing in the U.S. Users can also search and screen for Medicare-certified home healthcare providers in their area. Download checklists and tools to help assess senior housing and care options. Exchange ideas and join discussions by participating in Groups.

Medical Transport and Hospitality Housing

- **National Association of Hospital Hospitality Houses (NAHHH)**

Toll-free: 800-542-9730

Website: <http://www.nahhh.org>

NAHHH represents organizations that provide lodging (and service) for families receiving medical care away from home; furnishes information about hospitality homes in the caller's area; offers newsletter; and publishes an annual directory of facilities offering lodging.

- **National Patient Travel Center**

Toll-free: 800-296-1217

Website: <http://www.PatientTravel.org>

Family caregivers can receive help in locating air transportation for needy patients who need distant specialized medical evaluation, diagnosis or treatment. The National Patient Travel Helpline is available 24/7 and provides referrals to all major medical transport providers in the network.

Respite Resources

- **ARCH National Respite Network and Resource Center**

Website: <http://www.archrespite.org>

The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs in the United States; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

The ARCH National Respite Network includes the *National Respite Locator*, a service to help caregivers and professionals locate respite services in their community, the *National Respite Coalition*, a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels, and the *Lifespan Respite Technical Assistance Center* which is funded by the Administration for Community Living, *Administration on Aging (AoA)* in the US Department of Health and Human Services.

- **Catholic Charities**

703-549-1390

Website: <https://www.catholiccharitiesusa.org>

- **Easterseals**

Toll-free: 800-221-6827

Website: www.easterseals.com

Easter Seals provides a variety of services at 400 sites nationwide for children and adults with disabilities, including adult day care, in-home care, camps for special needs children and more. Services vary by site.

- **Faith in Action**

Toll-free: 877-324-8411

Website: <http://www.fiavolunteers.org>

e-mail: info@fiavolunteers.org

Faith in Action is an interfaith volunteer caregiving program of The Robert Wood Johnson Foundation. Faith in Action makes grants to local groups representing many faiths who volunteer to work together to care for their neighbors who have long-term health needs. There are nearly 1,000 interfaith volunteer caregiving programs across the country.

- **Family Friends**

National Council on the Aging, Inc.

202-479-6672

Website: <http://www.family-friends.org>

This group provides respite (and other services) by matching men and women volunteers over the age of 50 with families of children who have disabilities or chronic illness. Programs are located throughout the country.

- **Legacy Corps**

847-635-4600

Website: <http://www.lssi.org/senior-services/scs-legacy-corps-information.php>

Lutheran Social Services of Illinois (LSSI) Legacy Corps provides respite for veterans and military families, and decreases the caregiving burden and stress within these families. The program's mission is to help alleviate some of the demands of caregivers, and increase the potential of the caregivers to sustain loved ones at home. Volunteers stop by the home for a few hours a week, helping veterans or providing time off so that caregivers can run errands, see to other responsibilities, or just relax. Services are offered at no charge, regardless of income level, in most northern Illinois counties.

- **National Adult Day Services Association, Inc.**

Toll-free: 866-890-7357

Website: <http://www.nadsa.org>

This association provides information about locating adult day care centers in your local area.

- **National Respite Coalition (NRC)**

703-256-9578

Website: <http://www.archrespice.org/NRC.htm>

NRC provides a list of states that have respite coalitions. These state coalitions then list respite services available in their state. The majority of the information is focused on helping families of children with special needs, but lately there has been an effort to enlarge their referral base to include lifespan respite information. The NRC is working to gain passage of national lifespan respite legislation.

- **National Respite Locator Service**

Toll-free: 800-473-1727 ext. 222

Website: <http://www.respitelocator.org/index.htm>

Access a list of sites nationwide. While the vast majority focus on respite care for families of special needs children, the service now assists programs that provide respite for caregivers of adults and the elderly.

- **Shepherd's Centers of America**

Website: <http://www.shepherdcenters.org>

e-mail: staff@shepherdcenters.org

The organization provides respite care, telephone visitors, in-home visitors, nursing home visitors, home health aides, support groups, adult day care, and information and referrals for accessing other services available in the community. Services vary by center.

Training for Family Caregivers

Community-based resources may offer training and classes for family caregivers. Such resources may include: your local hospital; home care agencies; Area Agency on Aging, voluntary health agencies, and county and state departments of health.

- **American Red Cross**

202- 303-4498

Website: <http://www.redcross.org>

American Red Cross has developed training programs for family caregivers. You will need to check with your local chapter to find out if there are classes in your area.

- **National Family Caregivers Association**

Toll-free: 800-896-3650

Website: <http://www.thefamilycaregiver.org>

e-mail: info@thefamilycaregiver.org

CAN has developed an educational workshop to teach family caregivers to communicate more effectively with healthcare professionals. Check out the CAN Website to find out if there are workshops scheduled in your community.

Government Agencies:

U.S. Department of Health and Human Resources (Washington, D.C.)

Toll-free: 877-696-6775

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

Administration for Community Living (ACL)

http://www.aoa.acl.gov/AoA_Programs/Elder_Rights/Ombudsman/index.aspx

ACL brings together the efforts and achievements of the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the HHS Office on Disability to serve as the Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan.

National Association of Areas Agency on Aging (Washington, D.C.)

202-872-0888

Website: <http://www.n4a.org/>

- National Family Caregiver Support Program

Website: http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/

- Senior Services Centers

- Caregiver Respite Program

815-723-9713

Website: www.willcountyseniors.org

Veterans:

The Elizabeth Dole Foundation (Washington, D.C.) – Caring for Military Families

202-266-7932

Website: <http://elizabethdolefoundation.org>

The Elizabeth Dole Foundation teams with individuals and organizations across the country to build a powerful national coalition to address the significant gaps in support. The military caregiver crisis facing our nation will require holistic support and a broad range of resources. Prominent leaders from the public, private, nonprofit, labor and faith communities are stepping forward to support America’s hidden heroes—our nation’s military and veteran caregivers.

- **Legacy Corps**

847-635-4600

Website: <http://www.lssi.org/senior-services/scs-legacy-corps-information.php>

Lutheran Social Services of Illinois (LSSI) Legacy Corps provides respite for veterans and military families, and decreases the caregiving burden and stress within these families. The program's mission is to help alleviate some of the demands of caregivers, and increase the potential of the caregivers to sustain loved ones at home. Volunteers stop by the home for a few hours a week, helping veterans or providing time off so that caregivers can run errands, see to other responsibilities, or just relax. Services are offered at no charge, regardless of income level, in most northern Illinois counties.

National Care Planning Council

Website: http://www.longtermcarelink.net/ref_veterans_consultants.htm

The individuals on this page help veterans understand long term care benefits available through VA. This can include information on veterans health care, state veterans homes and veterans disability income benefits. These individuals place particular emphasis on Pension and Death Pension because these benefits are typically more useful for the elderly needing long term care. Pension is also known as "the aid and attendance benefit."

These individuals provide information about the aid and attendance benefit including what it is, who can qualify and what information and documentation are necessary in order to file a claim. They do not participate in any way in the application process unless that individual is accredited by VA. For all other individuals listed on this page, veteran households seeking help with filing a claim are directed to an appropriate veterans service organization or to a state or county veteran service representative or, where appropriate, they are encouraged to file a claim on their own.

The individuals listed on this page are private practitioners or in some cases representatives of veterans service organizations and are not connected with the Department of Veterans Affairs.

These individuals do not charge a fee for the preparation, presentation, or prosecution of a claim. Only those who are accredited attorneys or accredited representatives are involved in the processing of a claim.

U.S. Department of Veteran Affairs (Washington, D.C.)

Toll-free: 855-260-3274 (Caregiver Support Line)

Toll-free: 800-273-8255 (Press 1 for Veteran's Crisis Line)

Website: <http://www.va.gov/>

Website: http://www.caregiver.va.gov/support/support_services.asp

Mediation Organizations

The Center for Social Gerontology

734-665-1126

Website: <http://www.tcsg.org/med.htm>

This web site on **Mediation & Aging** was created to provide information and materials on the uses of mediation with older persons, particularly in situations in which guardianship or caregiver assistance is involved. Among the materials are TCSG's highly praised Adult Guardianship Mediation Manual, as well as training videos.

Mediate.com

541-345-1629

Website: <http://www.mediate.com>

National Association for Community Mediation

Website: <http://www.nafcm.org>

Senior Mediation and Decision-Making, Inc.

410-669-7587

Website: <http://www.senior-mediation.org>

Senior Mediation and Decision-Making, Inc. (SMDM), is a non-profit organization that promotes the development and provision of mediation, facilitation, coaching and related approaches to assist older persons, their families, and others have difficult conversations and make decisions, plan for the future, and prevent and resolve conflict around the transitions we may confront as we age.

Disease Specific and Health Related Agencies and Websites

This list was provided by the National Health Council

Website: <http://www.nhcouncil.org>

- **AIDS Healthcare Foundation**

323-860-5200

Website: <http://www.aids.health.org>

- **Alzheimer's Association**

Toll-free: 800-272-3900 (24/7 Hotline)

Website: <http://www.alz.org>

- **Alzheimer's Foundation of America**

Toll-free: 866-232-8484

Website: <http://www.alzfdn.org>

The mission of the Alzheimer's Foundation of America (AFA) is "to provide optimal care and services to individuals confronting dementia, and to their caregivers and families-through member organizations dedicated to improving quality of life." AFA unites more than 1,900 member organizations from coast-to-coast that are dedicated to meeting the educational, social, emotional and practical needs of individuals with Alzheimer's disease and related illnesses, and their caregivers and families. Under AFA's umbrella, these organizations collaborate on education, resources, best practices and advocacy —all resulting in better care for people affected by the disease.

- **American Autoimmune Related Diseases Association**

Toll-free: 800-598-4668

Website: <http://www.aarda.org>

- **American Brain Association**

703-761-0750

800-444-6443 National Brain Injury Information Center (Brain Injury Information Only)

Website: <http://www.biausa.gov>

- **American Cancer Society**

Toll-free: 800-ACS-2345

Website: <http://www.cancer.org>

- **American Diabetes Association**

Toll-free: 800-342-2383 (Patient Information)

Website: <http://www.diabetes.org>

- **American Foundation for AIDS Research**

Toll-free: 800-39-AMFAR 800-392-6327

Website: <http://www.amfar.org>

- **American Heart Association**

Toll-free: 800-AHA-USA1 800-242-8721

Website: <http://www.americanheart.org>

- **American Kidney Fund**

Toll-free: 800-638-8299 (Help Line)

Website: <http://www.kidneyfund.org> or <http://www.akfinc.org>

- **American Liver Foundation**

Toll-free: 800-GO-LIVER 800-465-4837 or 888-4HEP-USA 888-443-7872

Website: <http://www.liverfoundation.org>

- **American Lung Association**

Toll-free number to connect to local

American Lung Association offices: 800-LUNG-USA 800-586-4872

Website: <http://www.lungusa.org>

- **American Pain Foundation**

Toll-free: 888-615-PAIN 888-615-7246

Website: <http://www.painfoundation.org/>

- **American Parkinson Disease Association**

Toll-free: 800-223-2732

Website: www.apdaparkinson.org

- **American Stroke Association**

Toll-Free: 888-4-STROKE 888-478-7653

Website: <http://www.strokeassociation.org>

- **American Tinnitus Association**

Toll-free: 800-634-8978

Website: <http://www.ata.org>

- **ALS Association**

Toll-free: 800-782-4747

Website: <http://www.alsa.org>

- **Arthritis Foundation**

Toll-free 800-283-7800

Website: <http://www.arthritis.org>

- **Asthma & Allergy Foundation of America**

Toll-free: 800-7-ASTHMA 800-727-8462

Website: <http://www.aafa.org>

- **CancerCare**

Toll-free: 800-813-HOPE 800-813-4673

Website: http://www.cancercares.org/get_help/loved_one.php

Free telephone and in-person counseling with trained social workers; in-person, telephone and online support groups; educational workshops that you list to by telephone or over the Internet.

- **Cancer and Careers**

Website: www.cancerandcareers.org

Cancer and Careers is committed to changing the face of cancer in the workplace by providing a comprehensive website, free publications, and a series of support groups and educational seminars for employees with cancer.

- **Cancer Financial Assistance Coalition**

Toll-Free: 800-813-HOPE 800-813-4673

Website: www.cancerfac.org

CancerCare, a member of the coalition. Search the website by location or diagnosis to find organizations that provide financial help for your specific situation.

- **Cancer Research and Prevention Foundation**

Toll-free: 800-227-CRFA 800-227-2732

Website: <http://www.preventcancer.org>

- **CHADD**
(Children and Adults with Attention-Deficit/Hyperactivity Disorder)
Toll-free: 800-233-4050
Website: <http://www.chadd.org>
- **The COPD Foundation**
Toll-free: 866-316-2673 (COPD Caregiver Information Line)
Website: <http://www.copdfoundation.org>
- **Crohn's & Colitis Foundation of America**
Toll-free: 800-343-3637 (to order brochures and for general information)
Website: <http://www.ccfa.org>
- **Cystic Fibrosis Foundation**
Toll-free: 800-FIGHT CF 800-344-4823
Website: www.cff.org
- **Easterseals**
Toll-free: 800-221-6827
Website: www.easterseals.com
- **Epilepsy Foundation**
Toll Free: 800-332-1000
Website: <http://www.epilepsyfoundation.org>
- **The Foundation Fighting Blindness**
Toll-free: 888-394-3937
Website: <http://www.blindness.org>

- **Huntington's Disease Society of America**
Toll-free: 800-345-HDSA 800-345-4372
Website: <http://www.hdsa.org>
- **Kidney Cancer Association**
Toll-free: 800-850-9132
Website: <http://www.kidneycancerassociation.org>
- **The Leukemia & Lymphoma Society**
Toll-free: 800-955-4572
Website: <http://www.leukemia-lymphoma.org>
- **Lupus Foundation of America**
Toll-free: 800-558-0121 (Request Line)
Website: <http://www.lupus.org>
- **March of Dimes Birth Defects Foundation**
March of Dimes Resource Center
Toll-free: 888-663-4637
Website: <http://www.modimes.org>
- **Mesothelioma Web**
Toll-free: 877-367-6376
Website: <http://www.mesotheliomaweb.org>
- **Muhammad Ali Parkinson Center**
602.406.4931
Website: <http://www.maprc.com>

- **Multiple Sclerosis Association of America**
Toll-free: 800-532-7667
Website: <http://www.mymsaa.org>
- **Multiple Sclerosis Foundation**
Toll-free: 888-673-6287 (Program Services Assistance and MS Hotline)
Website: <http://www.msfocus.org>
- **Myasthenia Gravis Foundation of America**
Toll-free: 800-541-5454
Website: <http://www.myasthenia.org>
- **Myositis Association**
Toll-free: 800-821-7356
Website: <http://www.myositis.org>
- **National Aphasia Association**
Toll-free: 800-922-4622
Website: <http://www.aphasia.org>
- **National Cancer Institute**
Website: <http://www.cancer.gov>
- **National Down Syndrome Society**
Toll-free: 800-221-4602
Website: <http://www.ndss.org>

- **National Hemophilia Foundation**
Toll-free: 800-42-HANDI 800-424-2634
Website: <http://www.hemophilia.org>

- **National Mental Health Association**
Toll Free: 800-969-NMHA 800-969-6642
Website: <http://www.nmha.org>

- **National Multiple Sclerosis Society**
Toll-free: 800-FIGHT-MS 800-344-4867
Website: <http://www.nationalmssociety.org> or <http://www.nmss.org>

- **National Organization for Rare Disorders**
Toll-free: 800-999-6673
Website: <http://www.rarediseases.org>

- **National Osteoporosis Foundation**
202-223-2226
Website: <http://www.nof.org>

- **National Parkinson's Foundation**
Toll-free: 800-473-4636
Website: <http://www.parkinsons.org>

- **National Psoriasis Foundation**
Toll-free: 800-723-9166
Website: <http://www.psoriasis.org>

- **National Sleep Foundation**
202-347-3471
Website: <http://www.sleepfoundation.org>
- **Osteogenesis Imperfecta Foundation**
Toll-free: 800-981-BONE 800-981-2663
Website: <http://www.oif.org>
- **The Paget Foundation**
Toll-free: 800-23-PAGET 800-237-2438
Website: <http://www.paget.org>
- **Parkinson’s Disease Foundation**
Toll-free: 800-457-6676
Website: <http://www.pdf.org>
- **Partners Against Pain**
Toll-fee: 888-726-7535
Website: <http://www.partnersagainstpain.com>
- **Sjogren's Syndrome Foundation**
Toll-Free: 800-475-6473
Website: www.sjogrens.org
- **Spina Bifida Association of America**
Toll-free: 800-621-3141
Website: <http://www.sbaa.org>

- **Stroke Survivors Empowering Each Other (SSEEO)**

Toll-free: 888-988-8047

Website: <http://www.sseeo.org>

- **Tourette Syndrome Association, Inc.**

Toll-free: 888-4-TOURET 888-486-8738

Website: <http://www.tsa-usa.org>

- **Tuberous Sclerosis Alliance**

Toll-free: 800-225-6872

Website: <http://www.tsalliance.org>

- **United Ostomy Association**

Toll-free: 800-826-0826

Website: <http://www.uoaa.org>

- **United Cerebral Palsy**

Toll-free: 800-872-5827

Website: www.ucp.org

Administration on Aging (AoA)

National Family Caregiver Support Program (OAA Title III-E)

http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/

Authorizing Legislation: Section 371 of the Older Americans Act of 1965, as amended

- [The Purpose of the Program and How it Works](#)
- [Eligible Program Participants](#)
- [Data Highlight Extensive Services Provided to Caregivers](#)
- [Funding History](#)
- [Looking Back: NFCSP 10th Anniversary Celebration](#)
- [Resources and Useful Links](#)

The Purpose of the Program and How it Works

The National Family Caregiver Support Program (NFCSP), established in 2000, provides grants to States and Territories, based on their share of the population aged 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.

Families are the major provider of long-term care, but research has shown that caregiving exacts a heavy emotional, physical and financial toll. Many caregivers who work and provide care experience conflicts between these responsibilities. Twenty two percent of caregivers are assisting two individuals, while eight percent are caring for three or more. Almost half of all caregivers are over age 50, making them more vulnerable to a decline in their own health, and one-third describe their own health as fair to poor.

The NFCSP offers a range of services to support family caregivers. Under this program, States shall provide five types of services:

- information to caregivers about available services,
- assistance to caregivers in gaining access to the services,
- individual counseling, organization of support groups, and caregiver training,
- respite care, and
- supplemental services, on a limited basis

These services work in conjunction with other State and Community-Based Services to provide a coordinated set of supports. Studies have shown that these services can reduce caregiver depression, anxiety, and stress and enable them to provide care longer, thereby avoiding or delaying the need for costly institutional care.

Eligible Program Participants

While the Aging Network has always been involved with meeting the needs of both care recipients and family caregivers, by creating the National Family Caregiver Support Program, Congress explicitly recognized the important role that family caregivers occupy in our nation's long-term services and supports system. As of the 2006 Reauthorization of the Older Americans Act, the following specific populations of family caregivers are eligible to receive services:

- Adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older;
- Adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer's disease and related disorders;
- Grandparents and other relatives (not parents) 55 years of age and older providing care to children under the age of 18; and
- Grandparents and other relatives (not parents) 55 years of age and older providing care to adults age 18-59 with disabilities.

Each family caregiver presents his or her own unique needs and preferences for the types of programs and services they wish to receive at any given point in time. Further, the programs and services that are available vary from state to state and community to community. Fortunately, a number of national organizations and programs exist to help inform and support program development and innovation. Please see resources and links below for additional information regarding research, technical assistance and support for program development.

Data Highlight Extensive Services Provided to Caregivers

In FY 2010, the most recent year for which service data is available, over 700,000 caregivers received services through the National Family Caregiver Support Program. These services helped them better manage their caregiving responsibilities while ensuring their loved ones remained in the community for as long as possible. Service highlights include the following:

- **Access Assistance Services** provided over 1 million contacts to caregivers helping them locate services from a variety of private and voluntary agencies.
- **Counseling and Training Services** were provided over 125,000 caregivers with counseling, peer support groups, and training to help them better cope with the stresses of caregiving.
- **Respite Care Services** were provided more than 64,000 caregivers with 6.8 million hours with temporary relief – at home, or in an adult day care or institutional setting – from their caregiving responsibilities.

Data from AoA’s national surveys of caregivers of elderly clients shows:

- OAA services, including those provided through the National Family Caregiver Support Program, are effective in helping caregivers keep their loved ones at home;
- Nearly 40 percent of caregivers report they have been providing care for 2-5 years while approximately 29 percent of family caregivers have been providing care for 5-10 years;
- 77 percent of caregivers of program clients report that services definitely enabled them to provide care longer than otherwise would have been possible;

- 89 percent of caregivers reported that services helped them to be a better caregiver;
- Nearly half the caregivers of nursing home eligible care recipients indicated that the care recipient would be unable to remain at home without the support services; and
- Nearly 12 percent of family caregivers reported they were caring for a grandson or granddaughter.

To obtain more information about the services caregivers received, visit the [AGing Integrated Database](#) (AGID), an on-line query system based on AoA-related data files and surveys, and includes population characteristics from the Census Bureau for comparison purposes. The system allows users to produce customized tables in a step-by-step process and output the results in print or spreadsheet form. Information on NFCSP services and recipients is available through this database.

Funding History

Funding for Family Caregiver Support Services during the past four years is as follows:

FY 2008\$153,439,000

FY 2009\$154,220,000

FY 2010\$154,197,000

FY 2011\$153,911,000

Looking Back: The NFCSP 10th Anniversary Celebration

In 2010, the U.S. Administration on Aging (AoA) launched a yearlong celebration to commemorate the 10th Anniversary of the NFCSP. AoA worked in concert with national caregiver organizations and associations to mark this important achievement. Additionally, AoA encouraged states and communities to recognize the important role family and friends play in caring for friends and loved ones, and to celebrate the impact of caregiver support services, including the NFCSP. Learn more about the [NFCSP 10th Anniversary Celebration](#) and to access archived videos featuring the personal stories of family caregivers and other materials associated with the 10th Anniversary Celebration.