



# Helpful Caregiving Resources

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## About These Resources

There are many available resources for caregiving families, and new resources become available frequently. Here, we have identified some websites that may help you to find the resources which best meet your family's unique needs.

Although Our Family, Our Way does not endorse any one resource over another, we want to make sure that you are aware of a very valuable resource that is available to all Americans - your local, government-funded **Area Agency on Aging (AAA)**

AAAs are long-term care experts and can provide you with the most up-to-date information about resources in your area. Many AAAs also offer assessment and support services. Information on how to identify the AAA that serves your area is located on page 4.

### Important Notes:

All of the resources mentioned in this booklet are equipped with web links. All web links appear in blue and are underlined. If you are viewing this booklet on a computer with an internet connection, the web links will take you directly to the resource when you click on them. To keep the Helpful Resources booklet open on your computer and open the resource in a different tab, right-click on the web link and select "Open link in a new tab." Alternatively, you can copy and paste the web address into your internet browser, which will also take you to the resource.

As you think about helpful resources, be sure to consider and prioritize resources for care partners and persons living with care needs. For example, the organizations listed under Dementia Resources offer peer support and resources for people living with dementia as well as their care partners. It can be very important for persons with care needs to connect with others who are in similar situations.

## Area Agencies On Aging

**USAgging (formerly known as the National Association of Area Agencies on Aging)**

**Website:** [www.usaging.org](http://www.usaging.org)

Created by the Older Americans Act of 1965, Area Agencies on Aging (AAAs) respond to the needs of older adults in the communities they serve. They are advocates, planners, funders, and educators, as well as providers of information and referral services. Area agencies work with public and private partners to respond to the unique needs of older citizens and families in their areas.

AAAs around the nation provide direct support to caregivers, primarily through the **National Family Caregiver Support Program** (Title III E of the Older Americans Act), which was created in 2000. Services include respite care (temporary supervision of the person with care needs to provide rest for the care partner); individual counseling and support groups; care partner education classes/training; and emergency assistance.

There are currently over 600 AAAs nationwide which serve specific regions. USAgging represents and supports the national network of Area Agencies on Aging advocates for the Title VI Native American Aging Programs that help older adults and people with disabilities live with optimal health, well-being, independence, and dignity in their homes and communities.

The USAgging website has a tool to help you find the AAA that serves your area.

## AARP Resources for Care Partners

**Website:** [www.aarp.org/caregiving](http://www.aarp.org/caregiving)

In the Family Caregiving section of their website, AARP offers numerous web-based tools to help you find services, keep track of health records, and more.

### Caregiving Guides

These guides provide resources and tips for:

- » First-time caregiving
- » Caring for a loved one at home
- » Common caregiving conflicts
- » Long-distance caregivers
- » Caring for a loved one with dementia
- » Caring for a loved one with cancer

### Long-Term Care Calculator

AARP offers the long-term care calculator to assist families with finding the best, affordable care by estimating the cost of long-term care in a specific geographic area. Options include expenses for care in a nursing home, assisted living facility or adult day care, and use of a home health aide or homemaker service.

### Prepare to Care: A Caregiving Planning Guide for Families

Prepare to Care was developed by AARP and includes information on how to have vital conversations with older family members, organize important documents, assess care needs, and locate important resources.

## Administration for Community Living

**Website:** [www.acl.gov](http://www.acl.gov)

The Administration for Community Living manages a variety of programs (authorized by several statutes) including: providing assistance on health and wellness, protecting rights and preventing abuse, supporting consumer control, strengthening the networks of community-based organizations, funding research, and much more.

### National Family Caregiver Support Program

The National Family Caregiver Support Program (NFCSP) provides grants to states and territories to fund various supports that help caregiving families support older adults in their homes for as long as possible. NFCSP grantees provide five types of services:

- » Information about available services
- » Assistance in gaining access to the services
- » Individual counseling, organization of support groups, and training
- » Respite care
- » Supplemental services, on a limited basis

### Eldercare Locator

The Eldercare Locator is a public service of the U.S. Administration on Aging connecting you to services for older adults and their families. You can also reach them at 1-800-677-1116.

### LongTermCare.gov

LongTermCare.gov is maintained by the U.S. Administration on Aging and provides basic information on long-term care, Medicare and Medicaid, aging in place, advance care planning, and how to pay for long-term care.

## Advance Planning

Each state utilizes different legal forms for advanced directives such as durable powers of attorney, living wills, organ donation, and DNR (do not resuscitate). The following organizations provide helpful resources related to advance planning.

### **American Bar Association**

The American Bar Association provides access to free downloadable forms and information from state bar associations and other reputable state groups on their website:

[State-Specific Advance Directive Forms](#)

### **AARP**

AARP also provides a resource to assist in finding the correct forms for your state:

[Find Advanced Directive Forms By State](#)

### **National Institute on Aging**

The National Institute on Aging provides several resources to help caregiving families make decisions about the future:

[Advance Care Planning: Health Care Directives](#)

[Getting Your Affairs in Order](#)

[Organ Donation & Transplantation Resources for Older Donors and Recipients](#)

[Legal and Financial Planning for People with Dementia](#)

## ARCH National Respite Network and Resource Center

**Website:** [www.archrespite.org](http://www.archrespite.org)

The ARCH National Respite Network includes the [National Respite Locator](#), a service to help care partners 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 in the U.S. Department of Health and Human Services.

## Benjamin Rose Institute on Aging - Evidence-Based Programs for Caregiving Families

**Website:** [www.benrose.org](http://www.benrose.org)

Benjamin Rose Institute on Aging offers two evidence-based programs that may be helpful to caregiving families:

[BRI Care Consultation™](#) is a telephone and email-based care-coaching program designed to assist and support older adults living with chronic health conditions and their family and friend care partners. Trained Care Consultants collaborate with you and your loved one to:

- » Identify family priorities
- » Coordinate health care, community services, and family or friend support
- » Create action plans to meet your targeted needs
- » Reduce stress and strain

[SHARE for Dementia](#) is a care-planning program that empowers adults with early- or mid-stage dementia and their families get the most out of today while planning for tomorrow. The program is designed to engage both the person with dementia and their care partner in discussions about symptoms, communication, care values and preferences, healthy activities, and planning for the future.



## Caregiver Action Network

**Website:** [www.caregiveraction.org](http://www.caregiveraction.org)

Caregiver Action Network (CAN) is a non-profit organization providing education, peer support, and resources to family care partners across the country, free of charge. CAN serves a broad spectrum of family care partners such as parents of children with special needs, families and friends of wounded soldiers, young couples dealing with a diagnosis of multiple sclerosis, and adult children caring for parents with Alzheimer's disease.

### Family Caregiver Toolbox

CAN's Family Caregiver Toolbox provides links to a wide range of information to make your caregiving experience more successful.

## Centers for Medicare and Medicaid Services

**Website:** [www.cms.gov](http://www.cms.gov)

The Centers for Medicare and Medicaid Services (CMS) is part of the U.S. Department of Health and Human Services. Their website provides information about Medicare and Medicaid.

[www.medicare.gov](http://www.medicare.gov) provides information about signing up for Medicare and changing plans, estimating Medicare costs, what Medicare covers, drug coverage (Part D), supplements and other insurances, claims and appeals, and other forms and resources.

[www.medicaid.gov](http://www.medicaid.gov) gives general information about Medicaid. Medicaid programs vary by state and the Medicaid website also provides state overviews so you can learn about policies in your own state.

### Your Guide to Choosing a Nursing Home or Other Long-Term Services & Supports

This official government booklet explains how to find and compare nursing homes and other long-term care options, how to pay for nursing home care, your rights as a nursing home resident, and alternatives to nursing home care.

## Dementia Resources

### **Alzheimer's Association**

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

The Alzheimer's Association advances research to end Alzheimer's and other types of dementia while enhancing care for those living with the disease. The Alzheimer's Association works on a global, national, and local level to provide care and support for all those affected by Alzheimer's and other types of dementia. Their website provides information about Alzheimer's and other types of dementia, caregiving, care options, resources, and options for connecting with other families through their online community, local chapter activities, and support groups.

### **Association for Frontotemporal Degeneration**

**Website:** [www.theaftd.org](http://www.theaftd.org)

The Association for Frontotemporal Degeneration's mission is to improve the quality of life of people affected by frontotemporal degeneration (FTD) and to advance research, awareness, support, education, and advocacy. Their website offers options for peer support for people living with FTD through online resources and support groups

### **Dementia Action Alliance**

**Website:** [www.daanow.org](http://www.daanow.org)

Dementia Action Alliance is an advocacy organization dedicated to changing the stigma of dementia. Their website offers information about services and peer supports, including weekly online discussion groups, podcasts, an online Resources Center, and a national Speakers Bureau.

### **Dementia Alliance International**

**Website:** [www.dementiaallianceinternational.org](http://www.dementiaallianceinternational.org)

Dementia Alliance International is an organization whose membership is exclusively for people with a medically confirmed diagnosis of dementia from all around the world. Their website offers online support groups and other activities for their members, free of charge, in a number of different time zones.

### **Lewy Body Dementia Association**

**Website:** [www.lbda.org](http://www.lbda.org)

The Lewy Body Dementia Association is an organization dedicated to raising awareness of the Lewy body dementias (LBD), promoting scientific advances, and supporting people with LBD, their families, and care partners. The Association's purposes are charitable, educational, and scientific.

## Family Caregiver Alliance National Center on Caregiving

**Website:** [www.caregiver.org](http://www.caregiver.org)

The Family Caregiver Alliance National Center on Caregiving provides comprehensive caregiving information and advice, fact sheets, reports and studies, discussion groups, and newsletters for care partners, practitioners, policymakers, and researchers.

### Services by State

The Services by State tool helps caregiving families locate public, nonprofit, and private programs and services in specific areas. It includes resources in the following categories: care partner compensation, disease specific organizations, general information assistance, government health disability programs, legal help advocacy, living arrangement for persons with care needs, services for persons with care needs living at home, and services policies for family care partners.

### Holding a Family Meeting

This resource provides guidance on several aspects of holding a family meeting: Who Should Attend; How Should We Begin?; The Meeting; Potential Challenges; Win/Win Situations; and When Do You Need Outside Help? Where Can You Get It?

### How to Compensate a Family Member for Providing Care

A formal agreement among family members can provide a way to compensate a person providing care if he or she is no longer able to hold other employment. One way of protecting the care partner as well as the person receiving care is by putting the care relationship in writing. This is a binding agreement, also called a long-term care personal support services agreement, elder care contract, or family care or caregiver contract. Most often, it is called a personal care agreement.

## Geriatric Care Managers

### Aging Life Care Association

Website: [www.aginglifecare.org](http://www.aginglifecare.org)

An Aging Life Care Professional, also known as a Private Geriatric Care Manager, is a health and human services specialist who acts as a guide and advocate for families who are caring for older relatives or adults living with disability. The Aging Life Care Professional is educated and experienced in any of several fields including, but not limited to, nursing, gerontology, social work, or psychology. They are able to address a broad range of issues related to the well-being of their client. They often have knowledge about the costs, quality, and availability of resources in their communities.

## Mediation Services

### What Is Elder Mediation?

The National Care Planning Council provides this information about elder mediation: Elder mediation provides a forum for family decision-making. It is private, confidential, and completely voluntary. Mediators facilitate a purposeful and directed conversation in which family members are encouraged to express their interests and concerns. Meetings are informal and are held in locations which meet the family's needs, including private homes, mediators' offices, and senior living facilities.

### How to Choose an Elder Mediator

AARP provides some helpful tips on finding someone to help your family navigate difficult caregiving issues.

There is no national credentialing or formal licensing for elder mediators, and states have different requirements. Choose a mediator familiar with elder issues. For referrals, try these sources:

- » [Mediate.com](http://Mediate.com)
- » [National Care Planning Council](http://National Care Planning Council)

## National Academy of Elder Law Attorneys

Website: [www.naela.org](http://www.naela.org)

The National Academy of Elder Law Attorneys (NAELA) is dedicated to improving the quality of legal services provided to people as they age and people with special needs. Their website provides information about elder law and can assist you with finding an elder law attorney.

## National Alliance for Caregiving

**Website:** [www.caregiving.org](http://www.caregiving.org)

The National Alliance for Caregiving (NAC) is dedicated to improving quality of life for friend and family caregivers and those in their care, by advancing research, advocacy, and innovation. Since 1997, NAC has published the “Caregiving in the U.S.” studies which provide information on caregiving demographics and other factors affecting caregiving. The reports of these studies can be accessed for free through their website. The NAC website also provides links to many caregiving resources.

## National Association for Home Care & Hospice

**Website:** [www.nahc.org](http://www.nahc.org)

The National Association for Home Care & Hospice (NAHC) provides consumer information about the basics of home care and hospice and how to select a home care provider or hospice.

## National Hospice and Palliative Care Organization

**Website:** [www.nhpc.org](http://www.nhpc.org)

The National Hospice and Palliative Care Organization (NHPCO) provides free consumer information on hospice care and puts the public in direct contact with hospice programs.

## Next Step in Care

**Website:** [www.nextstepincare.org](http://www.nextstepincare.org)

Next Step in Care is a program of the United Hospital Fund that provides easy-to-use guides to help family caregivers and health care providers work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients.

## Rosalynn Carter Institute for Caregiving

**Website:** [www.rosalynncarter.org](http://www.rosalynncarter.org)

The Rosalynn Carter Institute establishes local, state, national, and international partnerships committed to building quality long-term, home- and community-based services with the goal of supporting caregivers, both family and professional, through efforts of advocacy, education, research, and service. The Institute offers information on a variety of caregiver support programs and products for caregivers. In 2017, the Rosalynn Carter Institute partnered with the Georgia Division of Aging Services to provide the Dementia Capable Webinar series for family caregivers.

## Services & Advocacy for LGBT Elders

**Website:** [www.sageusa.org](http://www.sageusa.org)

Services & Advocacy for LGBT Elders (SAGE) connects lesbian, gay, bisexual, and transgender (LGBT) older people to innovative services and programs. Through initiatives ranging from cultural programs to employment and health services, SAGE offers support to LGBT older people around the country. SAGE also provides counseling, information, support groups, and more to lesbian, gay, bisexual, and transgender caregivers.

## Veterans Administration Caregiver Support

**Website:** [www.caregiver.va.gov](http://www.caregiver.va.gov)

The Veterans Administration Caregiver Support Program provides support and services for families caring for veterans. The program offers training, educational resources, and connections with local care partner support programs for veterans including:

- » Caregiver Support Line
- » Caregiver Support Coordinator
- » Peer Support for Caregivers
- » Adult Day Health Care (ADHC) Centers
- » Home-Based Primary Care
- » Skilled Home Care
- » Homemaker and Home Health Aide Program
- » Home Telehealth
- » Respite Care
- » Home Hospice Care

