Involving and Supporting Family Caregivers in Care Planning and Delivery:
Resource List

This Resource Guide is not attributable to the Centers for Medicare & Medicaid Services (CMS). This Resource Guide was developed by Nancy L Wilson, Baylor College of Medicine.

Basic Resources for Caregivers

1. AARP – Home and Family Caregiving
   AARP provides a wealth of resources for individual caregivers including planning and organizing, benefits and insurance, legal, financial, senior housing and end of life care.

   For more information, please visit, http://www.aarp.org/home-family/caregiving/, or call (888) 687-2277.

2. The National Alliance for Caregiving
   The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. Areas of focus include caregiving research, innovation and technology, state and local coalitions on caregiving and international caring.

   For more information, please visit, http://www.caregiving.org/resources/caregiver-health/, or call (301) 718-8444.

3. Administration for Community Living
   The Administration for Community Living is a great resource, through the Department of Health and Human Services (HHS), providing links to a wealth of information designed to assist family members and caregivers.

   For more information, please visit, https://www.acl.gov/node/549, or call (202) 401-4634.

4. Elder Locator
   Elder Locator is a public service that works with older adults and their families to find help on a variety of subjects. Services can be filtered by topic area or geographic location.

   For more information, please visit, http://www.eldercare.gov/eldercare.net/, or call (800) 677-1116.

5. Health and Aging Foundation (part of the American Geriatrics Society)
   This resource provides specialized tips for long-distance caregivers including planning family meetings, choosing a primary caregiver, hiring a geriatric care manager, as well as other helpful information for caregivers.
For more information, please visit, http://www.healthinaging.org/resources/resource:tips-for-the-long-distance-caregiver/, or call (800) 563-4916.

6. Aging Life Care Association
This website provides information on geriatric care management providing a holistic approach to helping families dealing with ongoing health challenges. Aging Life Care professionals provide assessment and monitoring, planning and problem-solving, education, advocacy and family caregiver coaching. This website also provides links to educational seminars and podcasts, as well as information on the certification process for those seeking a career as an Aging Life Care manager.

For more information, please visit, https://www.aginglifecare.org, or call (520) 881-8008.

7. Family Caregiver Alliance
This website offers a state-by-state guide for families seeking services, as well as a guide to online and in-person support groups. This website also provides a menu of articles and informative briefs on practical topics, such as understanding dementia behaviors, communicating with your doctor, and digital technology for caregivers.

For more information, please visit, https://www.caregiver.org, or call (800) 445-8106.

8. U.S. Department of Veterans Affairs (VA)
The VA Caregiver Support page offers a useful set of tools tailored for caregivers of veterans including the VA Caregiver Medication Log and Questions to Ask a Veteran’s Health Care Provider. The VA also runs a telephone Caregiver Support Line for immediate assistance and questions about what services veterans may be eligible for. VA facilities have licensed Caregiver Support Coordinators who provide support by matching veterans with services and provide valuable information about available resources.

For more information, please visit, https://www.caregiver.va.gov or call (855) 250-3274.

9. Caregiver Action Network
The website provides videos on life as a caregiver, staying connected to your loved one, and finding support as well as a comprehensive Family Caregiver Toolbox covering Medicare, technology, financial planning, depression, and more.

For more information, please visit, http://caregiveraction.org or call (202) 454-3970.

Resources for Dementia Caregivers

1. The Alzheimer’s Association
The Alzheimer’s and Dementia Caregiving Center, offered by the Alzheimer’s Association, has a wide range of offerings, including what to expect at each stage of the disease, suggestions for activities and difficult behaviors, and a caregiver’s forum and message board for questions and
support. The 24 hour helpline is available seven days a week and provides reliable information and support day and night.

For more information, please visit [https://www.alz.org/care/](https://www.alz.org/care/) or call (800) 272-3900.

2. **The Alzheimer’s Disease Education and Referral Center (National Institute on Aging)**
The Alzheimer’s Disease Education and Referral Center provides information on Alzheimer’s including research and federal initiatives for caregivers and healthcare providers.

For more information, please visit, [https://www.nia.nih.gov/health/alzheimers](https://www.nia.nih.gov/health/alzheimers) or call (800) 438-4380.

3. **WebMD's Alzheimer's Disease Health Center**
This site provides an overview of different types of support services and counseling options for people affected by Alzheimer’s disease.

For more information, please visit, [http://www.webmd.com/alzheimers/guide/counseling-support](http://www.webmd.com/alzheimers/guide/counseling-support).

4. **The Family Caregiver Alliance’s National Center on Caregiving**
This center provides an excellent overview of dementia caregiving including what to expect and ways to deal with issues during early stage, middle stage and late stages of Alzheimer's disease.

For more information, please visit, [https://www.caregiver.org/alzheimers-disease-caregiving](https://www.caregiver.org/alzheimers-disease-caregiving) or call (800) 445-8106.

5. **Caring.com**
The Steps and Stages is a customizable personal resource to guide caregivers helping someone with dementia. It provides a custom care guide as well as support from caregivers facing the same stage.

For more information, please visit, [https://www.caring.com/steps-stages/alzheimers](https://www.caring.com/steps-stages/alzheimers) or call (800) 973-1540.

6. **U.S. Department of Veterans Affairs (VA)**
The VA offers a series of short videos about dementia in-home care, including home safety, legal matters, dealing with problem behaviors and learning relaxation techniques.

For more information, please visit, [http://www.ruralhealth.va.gov/education/dementia-caregivers/](http://www.ruralhealth.va.gov/education/dementia-caregivers/).

This program provides a variety of free support services for North Carolina residents including confidential personalized tips on caring for people with memory disorders, telephone help with
care decisions or coping strategies, current Alzheimer’s information packet, subscription to The Caregiver newsletter with research updates from the Bryan Alzheimer’s Disease Research Center at Duke. This program provides general resources for help in selecting and locating support groups, education programs, websites, books or training materials for family, volunteer, paraprofessional or professional care providers and a resource page with annotated list of publications, training materials and ordering information.

For more information, please visit http://www.dukefamilysupport.org or call (800) 646-2028.

**Mental Health and Respite Care Information for Caregivers**

1. **HelpGuide.org**
   A non-profit to mental health and well-being including an overview and basics of respite care as well as types of respite care services.

   For more information, please visit, https://www.helpguide.org/articles/parenting-family/family-caregiving.htm.

2. **National Caregivers Library**
   An extensive on-line library for caregivers with many helpful resources including a description and costs of adult day care.

   For more information, please visit, http://www.caregiverslibrary.org/home.aspx.

3. **National Respite Network and Resource Center (NRNRC)**
   The website includes the National Respite locator, a service to help caregivers and professionals locate respite services in their community.

   For more information, please visit, http://archrespite.org/home or call (703) 256-2084.

4. **Alzheimer’s Association**
   The caregiving pages provide caregivers of with information on respite care and ways to overcome concerns as well as information on Adult Day Care Services.

   For more information, please visit, https://www.alz.org/care/alzheimers-dementia-caregiver-respite.asp or call (800) 272-3900.

5. **iCareFamily**
   iCareFamily is a stress management skills training program for caregivers of individuals with memory problems. In collaboration with Stanford University, the Alzheimer’s Association and other organizations created online training videos to help caregivers overcome stressful situations in their caregiver role. The goal of this program is to teach skills and provide tools and resources to enhance the coping with caregiving and improve quality of life.
For more information, please visit, http://www.icarefamily.com.

Care Transitions Information for Caregivers

1. The United Hospital Fund
This website provides various resources for caregivers including guides for what to expect during a hospital stay and hospital-to-home discharge guide.

For more information, please visit, http://www.nextstepincare.org/Caregiver_Home/

2. The Care Transitions Program
This program works with individuals and their caregivers during times of care transition. The website provides tips and resources to mitigate problems during care transitions, such as how to recognize red flags and manage medications.

For more information, please visit, https://caretransitions.org/care-transitions-for-patients-and-family-caregivers/.

3. The National Transitions of Care Coalition (NTOCC)
This website provides information to help individuals and their caregivers better understand issues associated with transitioning from one health care setting to another. The resources available include a Patient Bill of Rights During Transitions of Care and a presentation from NTOCC on transitions of care.

For more information, please visit, http://www.ntocc.org/WhoWeServe/Consumers.aspx.

Evidence-Based Dementia Care Training for Caregivers

1. Alzheimer’s Disease Supportive Services Program (ADSSP) Training Resources Compendium
The ADSSP, run through the Administration on Aging, provides grants to states developing and implementing community-based services for individuals and caregivers impacted by Alzheimer’s disease and related disorders (ADRD). In addition, ADSSP has created reports compiled with training resources for both caregivers and professionals along with describing the experience of the various ADSSP grantees.


2. **UCLA Alzheimer's and Dementia Care Program**

   This program is designed to help individuals with dementia and their caregivers with the complex medical, behavioral and social needs of Alzheimer's disease and other types of dementia. The Dementia Care Managers are at the heart of the program and work with the individual's primary care doctor to develop and implement a personalized care plan. The website provides useful information for caregivers and health professional including access to educational training videos.

   For more information, please visit, [http://dementia.uclahealth.org](http://dementia.uclahealth.org) or call (310) 319-3222.