

# Resources for Individuals and Families

HOME AND COMMUNITY-BASED SERVICES  
FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



alzheimer's   
association™

A TOOLKIT FOR  
THE AGING NETWORK

  
INTERNATIONAL

# HOME AND COMMUNITY-BASED SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



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# About This Toolkit: Resources for Individuals and Families

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## Home and Community-Based Services for People with Dementia and Their Caregivers

Providing individuals and families with accurate information and streamlined access to needed dementia-capable services can empower caregivers and persons with dementia to make customized choices about their long-term care needs. **This toolkit is designed to provide states and communities with information and resources that will support individuals and families with Alzheimer's disease and related dementias.**

### The Resources for Individuals and Families Toolkit:

- Provides reasons for empowering consumers with dementia-capable choices and support.
- Offers an array of resources that are model programs or unique examples for state officials to use when developing programs. Many of these programs are funded by the Administration on Aging through the Alzheimer's Disease Demonstration Grants to the States (ADDGS) program.
- Describes how state officials can use information, resource materials, and model programs to offer consumers the opportunity to make informed decisions and choices about their long-term care needs. Information is provided on how to:
  1. Use state resources to make information about dementia and care options widely available.
  2. Train state and local information and referral staff, including those with single points of entry (SPOE), to identify cognitive impairment contacts and make appropriate referrals.
  3. Provide accurate information about, and access to, local care options and services.
  4. Enhance access to services through SPOEs, such as Aging and Disability Resource Centers (ADRCs).
  5. Engage in public information campaigns and provide resources to encourage individuals to plan ahead for long-term care needs.
  6. Make culturally appropriate materials accessible to diverse populations.
  7. Inform state personnel and caregivers about special concerns in a time of emergency.

This toolkit provides information on promising practices, with hyperlinks to material available on the Internet.

# Promising Practices: Resources for Individuals and Families

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## Home and Community-Based Services for People with Dementia and Their Caregivers

### Why Empower Consumers with Dementia-Capable Information and Access?

- Alzheimer's disease is a devastating degenerative disease that causes memory loss, challenging behavior problems, and severe functional limitations. According to the Alzheimer's Association's *2008 Alzheimer's Association Facts and Figures*, an estimated 5.2 million Americans have Alzheimer's disease. By 2050, the Alzheimer population may grow to 16 million. At age 65, one in eight people have some form of dementia and by age 85, nearly half experience Alzheimer's or a related dementia.
- An estimated 70 percent of people with dementia are living in the community at any one time. One in five family caregivers provide more than 40 hours of care per week, juggling job and family responsibilities.
- Alzheimer's disease and most other diseases and conditions that cause dementia are progressive. Alzheimer's lasts an average of 4 to 6 years from the time of diagnosis until death, but it can last as long as 20 years from the first onset of symptoms. Over time, the person's needs change—requiring caregivers to access new information to address current needs.
- Families with dementia most often turn to their physicians for information on supportive services. However, physicians are not always familiar with nonmedical community support services like adult day care, home-delivered meals, and in-home support services.
- Consumers, especially baby boomers, are turning to the Internet to find information on health and support services. Among Internet users aged 50 and over, 54 percent use the Internet to access this information.

### What Are Dementia-Capable Services?

To be dementia capable, individuals who assist consumers to access home and community-based services must be

- skilled at identifying people with Alzheimer's disease,
- knowledgeable about the kinds of services that can help people with dementia and their caregivers, and
- provide linkages to other agencies and community organizations that can help.

To make informed choices, consumers must be empowered to identify, understand, and access dementia-capable community services.

## Resources for Individuals and Families

States can engage in four key activities to address the needs of individuals and families:

1. Make information about dementia and dementia care options widely available
2. Train state and local information and referral staff to identify cognitive impairment contacts and make appropriate referrals
3. Provide accurate information about, and access to, local care options and services
4. Enhance access to services through SPOEs, such as ADRCs
5. Engage in public information campaigns and provide resources to encourage individuals to plan ahead for long-term care needs
6. Make culturally appropriate materials accessible to diverse populations
7. Inform state personnel and caregivers about special dementia concerns in times of emergency

## Promising Practices for Each Key Activity

### 1. Make information about dementia and dementia care options widely available

Dementia resources should be used to support families with cognitive impairment. State programs should

- Educate caregivers on the signs and symptoms of dementia
- Develop and post information that responds to people's concerns
- Publicize effective resources to help consumers make customized choices

#### A. Educate caregivers on the signs and symptoms of dementia

The Alzheimer's Association has developed a checklist of common [Warning Signs of Alzheimer's](#) to help persons recognize the differences between normal age-related memory changes and possible warning signs of Alzheimer's disease. To make this information widely available, states and community organizations can incorporate the warning signs into their consumer information initiative.

#### B. Develop and post information that responds to people's concerns

People with dementia and their families often struggle with the question of "when is it time?" to initiate a change in level of care or care setting. Because of the complexities of the condition, it is not always obvious when caregivers should ask for support. Here are examples of resources that states have developed to assist consumers in addressing this question.

- In their [Frequently Asked Questions](#) web page, the **New York** State Office for the Aging provides consumer information on prevention, symptoms, diagnosis, and treatment of Alzheimer's disease.
- **North Carolina's** Division of Aging and Adult Services offers a single-page document, titled [Alzheimer's and Dementia Web Resources](#), that lists state and local resources on diagnostic and treatment centers, Alzheimer's and dementia support services, family caregiver support and education, respite care and information programs, and national organizations, programs, and referral services.
- The **New York City** Department for Aging takes a more comprehensive, multilevel approach. New York City provides an Alzheimer's guidebook for consumers called [Community Care Options for the Alzheimer Family](#) that has assessment tools, referrals to community services and support groups, and guidance on medical, legal and financial issues.

### **C. Publicize effective resources to help consumers make customized choices**

The Alzheimer's Association's [CareSource™](#) is a suite of services that provides an easy-to-use, one-stop resource for everything someone needs to know to find and plan for care for a person with Alzheimer's. CareSource's new online suite of services helps to coordinate assistance from family and friends, locate senior housing, and receive customized care recommendations.

Any state or community organization can link to the Alzheimer's Association CareSource™ to enhance their dementia care online resources and provide immediate information on local home and community care services and support.

- [Lotsa Helping Hands](#) is an interactive calendar that allows anyone involved in care or support to log onto one convenient, private site and organize caregiving activities. It's easy to post dates and times for duties others have agreed to share, such as preparing meals, providing rides, running errands or keeping the person with dementia company.
- Alzheimer's Association's [Senior Housing Finder<sup>SM</sup>](#), powered by SNAPforSeniors<sup>®</sup>, is the first online nationwide database for locating dementia care. The tool allows the individual to search for licensed senior housing by geographic area, housing type, and availability.
- [Caregivers Message Board](#) allows caregivers to tap into a vibrant community of Alzheimer's caregivers for tips and emotional support.
- [Caregiving 101](#) provides information on products, free resources, and local training and workshops for caregivers.
- Alzheimer's Association's [CareFinder™](#), supported in part by the U.S. Administration on Aging, helps individuals to identify dementia care options that best meet their needs and preferences. CareFinder™ helps individuals recognize good care, communicate effectively with care providers and learn

about care payment sources. Several states have linked their resources to CareFinder™:

- **Virginia** links the CareFinder™ to its official state resource on health and aging called [Virginia's SeniorNavigator](#).
- **Arkansas** added the CareFinder™ link to their state's [Bridging the Gap](#) Alzheimer's information and support Web site. The link is located under *Other Resources*.
- **24/7 Helpline:** The Alzheimer's Association's 24/7 Helpline, supported in part by the U.S. Administration on Aging, provides reliable information and support to individuals affected by Alzheimer's disease or related dementias. The toll-free number, **1-800-272-3900**, is available anytime, day or night. The 24/7 Helpline serves people with memory loss and their families, caregivers, health care professionals, and the public. To assist citizens needing help after normal business hours, states can post the toll-free number on their Web sites and implement procedures to ensure that state-operated call centers refer people to the 24/7 Helpline after hours.

The 24/7 Helpline's highly trained and knowledgeable staff can help with: (1) understanding memory loss, dementia and Alzheimer's; (2) dealing with challenging behaviors; (3) obtaining general information about aging and brain health; (4) learning skills to provide quality care and to find the best care from professionals; (5) making legal, financial and living arrangement decisions; and (6) handling caregiver stress. Callers who do not speak English are assisted with the use of a translation service that features over 140 languages.

## **2. Train state and local information and referral staff to identify cognitive impairment contacts and make appropriate referrals**

State personnel serving seniors need training to identify and understand cognitive changes in older adults and make appropriate referrals.

**Minnesota** used funds from its Alzheimer's Disease Demonstration Grants to States (ADDGS) program to train staff on the statewide information system, Senior LinkAge Line™, to identify dementia contacts and provide needed information and referrals to community services. The [Senior LinkAge Line®](#) is part of Minnesota's Aging and Disability Resource Center (ADRC) network.

## **3. Provide accurate information about, and access to, local care options and direct services**

States can help consumers select local care options and direct services by making community level information widely available. States can provide local service information by linking directly to community organizations providing services or by developing and posting in-depth resource materials.

- One resource that can help link caregivers with support services in the community is the [local chapters](#) of the Alzheimer's Association. Local chapters provide a wide range of services including care consultation, referral, education and training, and support groups.

Specific examples of state resources providing community level information are:

- **Virginia's** [SeniorNavigator](#) allows consumers to identify local services using zip codes. To test how SeniorNavigator works, users can enter a Virginia zip code such as 22030, 22807, or 24270.
- [Aging and Disability Services Administration](#) in **Washington** has a comprehensive Web site that covers issues such as getting started, finding care, paying for care, obtaining information on various chronic diseases, and planning for the future. In the *Find Local Services, Information, and Resources* section, users are directed to click on the county map in which services are needed to retrieve information on their local aging service agency.

#### 4. Enhance access to services through SPOEs, such as ADRCs

States can enhance access to services by creating single points of entry (SPOE) systems such as [ADRCs](#) that reduce service fragmentation and simplify access to dementia-capable long-term supports and services.

Many state ADDGS programs work with ADRC staff in their planning efforts. State government dementia care experts and their partner organizations provide information about dementia resources and can facilitate connections to community service providers. Some states have used ADDGS grant funds to enable their ADRCs to become more dementia capable. Examples of states that have used their ADDGS funding to collaborate with their ADRCs follow:

- **Maine** is using ADDGS grant funds to support an Alzheimer's expert at the Eastern Agency on Aging, one of the state's AAA and its first ADRC. The ADDGS grant also supports a family caregiver support program that is based at the Eastern Agency on Aging. People who contact the ADRC about persons with dementia are referred immediately to the on-site Alzheimer's expert and family caregiver support program.
- **Minnesota** used ADDGS funds to make its ADRC dementia capable. For example, it revised the referral database used by staff of the state's telephone information system, [Senior LinkAge Line®](#), so that when contacts about a person with dementia are identified, the caller is referred first to the Alzheimer's Association for help with defining care needs and selecting service providers. Changes were also made to computerized intake and self-assessment forms. [ADRCs, Alzheimer's Disease, and Dementia](#) offers tools, resources, instruments, and a review of Minnesota's model ADRC.

- **North Carolina** has supported an innovative ADDGS program, [Project C.A.R.E.](#) (Caregiver Alternatives to Running on Empty), that provides comprehensive respite support and linkage to services for family caregivers by a family consultant. The family consultant is based in the Alzheimer's Association chapter and works closely with the state's ADRCs in two counties to encourage them to refer families of people with dementia to Project C.A.R.E.
- **Rhode Island** used ADDGS funds to support two, half-time staff members at the ADRC. The two staff members are dementia specialists; they provide counseling, referrals, and assistance in arranging services and supports for people with dementia, with backup from the local Alzheimer's Association chapter as needed.
- **West Virginia** supports an innovative program, Continuum of Contact, which provides a structured 6-month family caregiver information and support program that is based at the Alzheimer's Association chapter. The state's ADRCs have been encouraged to refer families of people with dementia to the program. ADDGS grant funds are also being used to support ADRC involvement in a project to increase the availability and use of dementia-capable hospice care.

## 5. Engage in public information campaigns and provide resources to encourage individuals to plan ahead for long-term care needs

One of the best ways for consumers to exercise choice with respect to long-term care options is to have legal and financial resources available when they are needed. Getting a diagnosis of Alzheimer's or dementia does not mean that people cannot make decisions about their own future. In fact, people in the early stages of the disease or with early-onset Alzheimer's can find planning for their own future needs empowering. Persons with Alzheimer's should participate in planning for their own long-term care needs to the greatest extent possible—and it is important to begin planning as soon as the diagnosis is made.

- Encourage states and consumers to take full advantage of the resources available through the U.S. Department of Health and Human Services' [National Clearinghouse for Long-Term Care Information](#) and the [Own Your Future](#) campaign. Individuals can learn about the importance of financial planning, advance directives for health care, care options, long-term care insurance, and home safety and modification. These are important issues to people with Alzheimer's and their families. [CareFinder™](#) is an additional resource that provides information on legal topics and [state specific](#) planning tools.
- Through the **Connecticut** Partnership for Long Term Care, the state has joined with private insurance companies to provide Connecticut residents with unbiased information about long-term care, financial planning, advance directives, understanding long-term care insurance, print information, and

forums that are free and open to the public. The [Consumer Information](#) page contains information on public and private long-term care programs.

## **6. Make culturally appropriate materials accessible to diverse populations**

Cultural barriers concerning contacts with government agencies and deeply ingrained stigmas associated with Alzheimer's disease amplify low awareness of the disease among many cultural communities. These barriers and stigmas make accessing services particularly difficult. To realize the goal of prolonging homecare in an increasingly diverse society, state and community care systems can help increase dementia awareness and caregiver support among culturally diverse populations. These goals can be achieved by:

- Engaging in multicultural programming
- Publicizing the availability of multicultural resources

### **A. Engaging in multicultural programming**

- The State of **Florida** had a statewide program that served more than 100,000 diverse individuals coping with care transition. REACHOUT Florida educated multicultural communities about Alzheimer's disease through partnerships with local and statewide minority organizations. In part, this program was modeled after Florida's ADDGS program, known as S.T.A.R.S and Beyond. REACHOUT Florida was funded by the Florida Department of Elder Affairs and was implemented in partnership with the Florida Chapters of the Alzheimer's Association. The program was the primary catalyst that incorporated diversity outreach into state-funded Alzheimer services.

### **B. Publicizing the availability of multicultural resources**

State resources can be applied to publicize and provide increased access to multicultural information. Resources that can be used for this purpose could include state Web sites, standard information provided at trainings of statewide ADRC and Information and Referral staff, and resource guides providing links to local community services. These state-supported information sources can include multicultural resources as a regular part of the information they provide.

Examples of materials that states can publicize include:

- Resources developed by ADDGS grantees for limited-English speaking populations: Arabic, Assyrian, Bosnian, Chinese, Hindi, Korean, Polish, Spanish, Urdu, and Vietnamese. This material can be found on the Administration on Aging's [Alzheimer's Disease Program](#) Web site.
- Culturally appropriate brochures developed by the Alzheimer's Association to help recognize symptoms and provide information to assist with transitions in care. A few examples of these kinds of materials include:

- [What's Happening to Grandpa?/Que La Pasa Al Abuelito?](#)
- [Staying Strong: Stress Relief for the African American Caregiver](#)
- [Introduction to Alzheimer's Disease](#) (in Chinese) and [The Asian American Dementia Care Network](#)
- The Alzheimer's Association's Web site has a [diversity toolkit](#), which includes: [Latino](#), [African American](#), [Chinese](#), and [Korean](#) resources that outline information on caring for family members with Alzheimer's disease and other related dementias.

## **7. Inform state personnel and caregivers about special dementia concerns in times of emergency**

Because dementia affects cognitive ability and judgment, effective emergency preparedness must involve caregivers in addition to state and local governmental entities. Caregivers can find themselves unprepared to assume full responsibility for a loved one suddenly discharged from an assisted living or other residential facility. While any type of disaster causes unavoidable disruption, careful preparation by family caregivers and state and local authorities can mitigate the devastating effects on this vulnerable population.

Disaster preparedness information for people with dementia should be made widely available to state agency personnel and local first responders. The following materials are examples of resources that states can distribute and publicize to inform caregivers and first responders about the special needs of people with dementia.

- The Administration on Aging's *Emergency Assistance Guide* offers a comprehensive set of technical assistance materials to help the Aging Network as others prepare and plan for the management of major emergencies or disasters.
- The Alzheimer's Association's [Disaster Preparedness Fact Sheet](#) provides specific information and tips on facing disasters for those affected by dementia.

## **Additional Information**

The Administration on Aging has developed eight toolkits in this series that focus on different aspects of providing home and community-based services to people with dementia and their caregivers. These online toolkits are available at [AoA's Alzheimer's Program website](#). Toolkit subjects include:

1. Consumer-Directed Care
2. Disaster Preparedness
3. Resources for Individuals and Families
4. Serving African American Families
5. Serving Asian and Pacific Islander Families
6. Serving Hispanic Families
7. Single Point of Entry Systems
8. Supporting Family Caregivers