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# Dementia Capability Toolkit

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## **Dementia Capability Toolkit**

States serve a substantial number of people with dementia and their family caregivers living in the community through their Aging Networks and long-term services and supports (LTSS) systems. Serving this community-based population effectively involves accommodating the needs of a population that, in addition to memory loss, experiences a variety of physical, cognitive, and behavioral symptoms resulting from dementia, along with other medical conditions. In dementia-capable systems, programs are tailored to the unique needs of people with Alzheimer's disease or other dementias, and their caregivers:

- Information and assistance services have a method to identify people with possible dementia. Individuals with possible dementia receive a recommendation for follow-up with a physician.
- Options counseling staff communicate effectively with persons with dementia and their family caregivers and know what services this population is likely to need.
- Eligibility criteria and resource allocation take into account the impact of dementia on the need for services.
- Publicly and privately financed services are capable of meeting the unique needs of persons with dementia and their caregivers.
- Self-directed services ensure that persons with dementia and their caregivers are supported in their decision-making and involve others who can represent the person's best interest when necessary.
- Workers who interact with persons with dementia and their caregivers have appropriate training in identifying a possible dementia in persons that they serve, the symptoms of Alzheimer's disease and other dementias, the likely illness trajectory, and services needed.
- Quality assurance systems measure how effectively individual providers, the Aging Network, and LTSS systems serve persons with dementia and their family caregivers.

This toolkit complements the issue brief titled *Making the Long-Term Services and Supports System Work for People With Dementia and Their Caregivers* by identifying resources that states and communities can use to design initiatives to ensure that programs are dementia-capable.

### **Prevalence and Impact of Dementia**

A substantial number of people have a cognitive impairment related to dementia. A definitive diagnosis of Alzheimer's disease and other dementias is difficult, so national estimates of the number of people with dementia vary, ranging from about 3 million people over the age of 65 in the period 1999 to 2001 to 5.4 million Americans of all ages having Alzheimer's disease in 2011. When assessing the needs of persons with dementia and caregivers in the community, it is important to understand the number of persons affected and their unique needs for services and

programs. This section includes resources that provide national and state-by-state information addressing the prevalence and impact of dementia.

1. Tools for understanding prevalence

- a. *Alzheimer's Disease Facts and Figures*, Alzheimer's Association (2011). A statistical resource that is published annually for United States data related to Alzheimer's disease and other dementias.

[http://www.alz.org/national/documents/Facts\\_Figures\\_2011.pdf](http://www.alz.org/national/documents/Facts_Figures_2011.pdf)

- b. State-by-State Caregiver Statistics, Family Caregiver Alliance, 2011.

- i. *Estimated Prevalence and Economic Value of Family Caregiving By State*. A state-by-state analysis of family caregivers, hours of caregiving provided, and an estimated market value calculated by the Family Care Alliance and the National Family Caregivers Association.

[http://caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1805](http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1805)

- ii. *State Profiles*. State profiles provide background characteristics related to caregiving, long-term care spending, and information on persons receiving care; state system of home and community-based services; state program information; and information on consumer-directed care options.

[http://caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1789](http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1789)

2. Tools for learning about the impact of Alzheimer's disease and its effects on the individual and the family

- a. *Understanding Stages and Symptoms of Alzheimer's Disease*, National Institute on Aging. Addresses common changes in mild, moderate, and severe Alzheimer's disease. <http://www.nia.nih.gov/NR/exeres/6739F4B3-C1A9-4564-8AC3-77DC1315974E.htm>

- b. *The Basics: Memory Loss, Dementia and Alzheimer's Disease*, Alzheimer's Association. An online training that includes information on Alzheimer's disease and related dementias, causes and risk factors, stages of the disease, and treatment.

<http://elearning.alz.org/Default.aspx>

- c. *CDC Features: Alzheimer's Disease*, Centers for Disease Control and Prevention. A web page providing a brief overview of Alzheimer's disease and the effects on the individual and the family. <http://www.cdc.gov/Features/Alzheimers/index.html>

- d. *HBO Documentary: The Alzheimer's Project*, Home Box Office. A four-part television documentary series with 15 short supplemental films, and a website that addresses personal and family experiences with the disease, issues for children, and care needs for those affected. <http://www.hbo.com/alzheimers/>

- e. *Caring for a Person with Alzheimer's Disease*, National Institute on Aging. An easy-to-understand guide for caregivers of persons with Alzheimer's disease. The guide is

divided into sections: understanding Alzheimer's disease; caring for a person with Alzheimer's disease; caring for yourself; when you need help; the medical side of Alzheimer's disease; coping with the late stages of Alzheimer's disease; and other information. The guide contains quotations from individuals who were part of Alzheimer's disease support groups at Duke University.

<http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/>

- f. *AlzBrain.org*, Dementia Education & Training Program, Alabama Department of Mental Health and Mental Retardation. Provides information for family caregivers, professionals, and persons concerned about memory loss. <http://www.AlzBrain.org>

## Identification and Awareness of a Possible Dementia

Although there is no cure, it is important that a person be diagnosed as early in the disease process as possible. An early diagnosis allows the individual and the family to plan for the future, to participate in care planning, and to take advantage of available treatments. The process of getting a diagnosis involves education and awareness, screening and assessment, and a comprehensive examination. This section provides warning signs that can be used as an education tool and various assessment instruments for cognitive impairment that include brief mental status tests and instruments for informant interviews. A definitive diagnosis of Alzheimer's disease or a related dementia requires a comprehensive examination by a trained medical professional that includes a medical and psychiatric history, a physical and neurological exam which may include brain imaging, laboratory tests (blood and urine), an evaluation of the person's functional ability, a mental status exam, and a family or caregiver interview.

### 1. Tools for identifying a possible dementia

- a. *Know the 10 Signs*, Alzheimer's Association. Webpage provides a variety of resources including the 10 Warning Signs of Alzheimer's, a doctor's appointment checklist, a free online course, and information on the importance of early detection. Tools are designed for consumers and results can be shared with the doctor. [http://www.alz.org/alzheimers\\_disease\\_know\\_the\\_10\\_signs.asp](http://www.alz.org/alzheimers_disease_know_the_10_signs.asp)
- b. *Mini-Cog*, Soo Borson. A three-item instrument used for mental status assessment. It does not require prior training of professionals on administration and scoring of the assessment. Borson S; Scanlan JM; Brush M; et al. "The Mini-Cog: A cognitive 'vital signs' measure for dementia screening in multi-lingual elderly." *International Journal of Geriatric Psychiatry*. 2000;15:1021-1027. [http://onlinelibrary.wiley.com/doi/10.1002/1099-1166\(200011\)15:11%3C1021::AID-GPS234%3E3.0.CO;2-6/abstract;jsessionid=3A9A683D523413324D28D116E7A2C5B8.d01t04?systemMessage=Wiley+Online+Library+will+be+disrupted+4+June+from+10-12+BST+for+monthly+maintenance](http://onlinelibrary.wiley.com/doi/10.1002/1099-1166(200011)15:11%3C1021::AID-GPS234%3E3.0.CO;2-6/abstract;jsessionid=3A9A683D523413324D28D116E7A2C5B8.d01t04?systemMessage=Wiley+Online+Library+will+be+disrupted+4+June+from+10-12+BST+for+monthly+maintenance). Full Instrument Available in: Hazzard WR. et al. (Eds). (2003). *Principles of Geriatric Medicine and Gerontology*, 5<sup>th</sup> edition. New York: McGraw-Hill Publishers. p157-p168.

- c. *General Practitioner Assessment of Cognition (GPCOG)*, Henry Brodaty. Includes six items for the person and other items for an informant. Screening test is designed to be administered by general practitioners and other experienced interviewers in a general practice setting. Brodaty H; Pond D; Kemp NM; et al. "The GPCOG: A new screening test for dementia designed for general practice." *Journal of the American Geriatrics Society* 2002;50(3):530-534.  
<http://onlinelibrary.wiley.com/doi/10.1046/j.1532-5415.2002.50122.x/abstract?systemMessage=Wiley+Online+Library+will+be+disrupted+4+June+from+10-12+BST+for+monthly+maintenance>. Link to assessment tool: <http://www.gpcog.com.au/>

## 2. Informant interview tools

A family member or close friend or neighbor of the person is often more likely to be able to recognize the decline in cognitive function that is a component of dementia. It is important to involve them in the assessment process as an informant. These are tools specifically designed for key informants such as family members or close friends.

- a. *AD-8*, James Galvin. An eight-item informant interview instrument that can be given to the respondent for self-administration or can be read aloud. If an informant is not available, the AD-8 can be used with the person with possible dementia. Scoring guidelines are available and administration of the instrument does not require prior staff training. Galvin JE; Roe CM; Powlishta KK; et al., "The AD8: A brief informant interview to detect dementia." *Neurology* 2005;65:559-564.  
<http://www.neurology.org/content/65/4/559>
- b. *Dementia Severity Rating Scale*, Christopher Clark. An informant-based, multiple-choice questionnaire that assesses severity from the mildest to the most severe stages in the major functional and cognitive domains affected in Alzheimer's disease. It can be implemented with a minimum of professional staff time and training. Clark CM; and Ewbank DC. "Performance of the Dementia Severity Rating Scale: A caregiver questionnaire for rating severity in Alzheimer disease." *Alzheimer Disease and Associated Disorders* 1996;10(1):31-39.  
[http://journals.lww.com/alzheimerjournal/Abstract/1996/01010/Performance\\_of\\_the\\_Dementia\\_Severity\\_Rating\\_Scale\\_.6.aspx](http://journals.lww.com/alzheimerjournal/Abstract/1996/01010/Performance_of_the_Dementia_Severity_Rating_Scale_.6.aspx)

## 3. Modified assessment procedures

Some states, including Missouri and Minnesota, have modified existing assessment procedures to identify dementia.

- a. Missouri's Project Learn MORE uses the AD-8 developed by Dr. James Galvin as part of a state-wide formalized identification and referral process that is being delivered through the Area Agencies on Aging and four Alzheimer's Association chapters.
- b. Minnesota's ADRC Online Assessment Form for family caregivers and professionals includes dementia-specific questions in intake and assessment protocols and online

assessment forms.

<http://www.longtermcarechoices.minnesotahelp.info/Questions.aspx?StepID=4>

4. Government-funded assessment clinics
  - a. *Alzheimer's Disease Centers*, National Institute on Aging. At major medical institutions across the country, Centers offer diagnosis and medical management; information about the disease, available services and resources; and opportunities for volunteers to participate in drug trials, and other clinical research projects. <http://www.nia.nih.gov/Alzheimers/ResearchInformation/ResearchCenters/>
  - b. *California Alzheimer's Disease Centers*, California Department of Public Health. A network of 10 dementia care Centers of Excellence at California medical schools established to improve Alzheimer's disease health care delivery, provide specialized training and education to health care professionals and others, and advance the diagnosis and treatment of Alzheimer's disease. <http://cadc.ucsf.edu/cadc/>

### **Measuring Functional Ability for Care Planning and Resource Allocation**

The need for assistance to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs) can be determined with general assessment instruments developed by Katz et al. (1963), Lawton and Brody (1969), and numerous others. Some researchers and clinicians have developed assessment instruments intended specifically for people with cognitive impairment and dementia. Some of these instruments measure IADLs and ADLs, and specifically identify the kinds of difficulties people with cognitive impairment often experience in performing daily activities. These measures are important in determining whether people with cognitive impairment meet functional impairment eligibility standards for government and private programs and for deciding how many resources to allocate to these individuals.

1. *Dependence Scale*, Yaakov Stern. Rating is based on informant responses to 13 questions about functional activities. The scale is sensitive to medication effects, psychosis, and other symptoms. It has been used as a predictor of nursing home placement. The Dependence Scale is designed to be administered by a trained professional interviewer. Stern Y; Albert SM; Sano M; et al., "Assessing patient dependence in Alzheimer's disease." *Journal of Gerontology: Medical Sciences* 1994;49(5):M216-M222. <http://geronj.oxfordjournals.org/content/49/5/M216.abstract>
2. *Direct Assessment of Functional Status (DAFS)*, David Lowenstein. Includes observation and rating on tasks in seven functional domains, including time orientation, transportation use, financial skills, shopping skills, and eating skills. The assessment is designed to be administered by a trained professional interviewer. Ref: Lowenstein DA; Amigo E; Duara R; et al. "A new scale for the assessment of functional status in Alzheimer's Disease and related disorders." *Journal of Gerontology* 1989;44(4):p114-p121. <http://geronj.oxfordjournals.org/content/44/4/P114.abstract>. Full Instrument is available in: Burns A, Lawlor B & Craig S. (1999). *Assessment scales in old age psychiatry*. London: Martin Dunitz. p140-p141.

3. *Self-Care Performance Tool*, Joan Thralow. Includes observation and rating on four self-care activities. This tool requires administration by a trained professional interviewer. Thralow JU; and Rueter MJS. "Activities of daily living and cognitive levels of function in dementia." *The American Journal of Alzheimer's Care and Related Disorders & Research* 1993;8(5):14-19. <http://aja.sagepub.com/content/8/5/14.abstract>

### **Information, Assistance, and Options Counseling**

Some people with dementia and their families can arrange for community services and the support they need if they are given a list of local agencies and providers. Others need more assistance to define their service needs, select a provider that can accommodate dementia-related care needs, and initiate the service. People with dementia need assistance with these tasks because of their cognitive impairments and families may need assistance because caregiving activities are overwhelming to them.

Below is a brief description of available community resources. It is often difficult to know what type of care is best for a person with dementia. A person's care needs depend on how independently he or she can do everyday things. It is important to understand a person's functional ability when making any kind of care transition.

- **Early Stage Socialization Programs**—In the beginning stage of Alzheimer's disease or a related disorder, individuals have special needs that may be overlooked. Support groups and socialization programs aimed at persons with early-stage Alzheimer's help identify some of these needs and provide suggestions to assist early-stage individuals and their caregivers.
- **Adult Day Care**—An adult day center provides care outside the home, and in this setting, people can socialize, participate in activities, and get health care. Home and community-based services, such as those funded through the Older Americans Act and Medicaid, help persons with dementia maintain their independence and dignity in their homes and communities. Programs include transportation; case management; personal care, chore, and homemaker assistance services; legal services; mental health services; and adult day care. Independent Living communities are usually in a small, easy-to-maintain private apartment or house within a community of seniors. No personal care or medical care is provided, but other services may be available such as transportation or recreation activities.
- **Assisted Living residences** generally provide personal and supportive services, recreational activities, meals, housekeeping, laundry, and transportation. Definitions and specific regulations differ from state to state.
- **Nursing Homes** may provide a full range of care needs, including skilled care and long-term care.



## Information, Referral, and Assistance

People with dementia and their caregivers need information about the services and supports available in their local communities so they can make informed choices about selecting services that will best meet their needs.

1. *ElderCare Locator* 1-800-677-1116, Administration on Aging, U.S. Department of Health and Human Services. Connects older Americans and their caregivers with information on senior services, including information on finding help within the local community, and also provides tools, links, and other resources.  
<http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>
2. *Alzheimer's Association Helpline* 1-800-272-3900, Alzheimer's Association, funded in part by the Administration on Aging. Serves people with Alzheimer's disease and related dementias, caregivers, health care professionals, and the public, providing information and support, 24 hours a day, 7 days a week. Provides confidential care consultation, help in caller's preferred language, and referrals to local community programs and services.  
[http://www.alz.org/we\\_can\\_help\\_24\\_7\\_helpline.asp](http://www.alz.org/we_can_help_24_7_helpline.asp)
3. *Care Crossroads*, Alzheimer's Foundation of America. An interactive community of care that provides caregivers with opportunities to meet with other caregivers, learn about Alzheimer's disease and connect with social workers and other professionals to ask questions and get resources.  
[http://www.carecrossroads.org/cms/index.php?option=com\\_content&view=article&id=3&Itemid=6](http://www.carecrossroads.org/cms/index.php?option=com_content&view=article&id=3&Itemid=6)
4. *Family Caregiver Alliance*. Offers programs at national, state, and local levels to support and sustain caregivers including the Family Care Navigator to help caregivers locate support services in their communities. <http://www.caregiver.org/caregiver/jsp/home.jsp>
5. *Alzheimer's Disease Education and Referral Center (ADEAR)* 1-800-438-4380, National Institute on Aging. Provides information about research on causes, treatment, cures, and diagnostic tools. Material is carefully researched and thoroughly reviewed by NIA scientists and health communicators for accuracy and integrity.  
<http://www.nia.nih.gov/Alzheimers/>
6. *Michigan Dementia Coalition*. Website offers a variety of resources for consumers and professionals including a respite care resource list, professional education and training materials, and research-based recommendations for effective caregiver interventions.  
<http://www.dementiacoalition.org>
7. *AlzBrain.org*, Dementia Education & Training Program, Alabama Department of Mental Health and Mental Retardation. Provides information for family caregivers, professionals and persons concerned about memory loss. <http://www.AlzBrain.org>

## Options Counseling and Assistance

Options counselors can help individuals with Alzheimer's disease and their caregivers make the appropriate choices on insurance and financial planning, legal matters, care transitions, long-term care, and end-of-life care.

1. *Evidence-Based Care Transitions Models: Strategies that Support Persons with Dementia and Caregivers*. A presentation given at the 2011 ADSSP Grantee meeting that provides information on specific tools and approaches needed to provide seamless and coordinated care. [http://www.adrc-tae.org/tiki-download\\_file.php?fileId=30451](http://www.adrc-tae.org/tiki-download_file.php?fileId=30451)
2. *Massachusetts Alzheimer's Disease Supportive Service Project*. Massachusetts Executive Office of Elder Affairs, the Alzheimer's Association and the Aging and Disability Resource Centers (ADRCs). ADSSP program to strengthen the referral network, enhance capacity of ADRCs to identify persons with dementia, and to increase the expertise of options counselors in recommending services. <http://www.adrc-tae.org/tiki-index.php?page=MassachusettsPage>
3. *Wisconsin Dementia Outcomes Care Planning Tool*, Wisconsin Department of Health and Family Services. Tool developed specifically for care managers and other providers, provides a structured approach for planning and examining quality of life issues with people who have dementia. <http://www.dhs.wisconsin.gov/aging/dementia/Dementia%20Outcomes%20Care%20Plan%20Tool.pdf>
4. *Hospitalization Happens: A Guide to Hospital Visits for Individuals with Memory Loss*, National Institutes on Aging (originally developed by the North Carolina Division of Aging and Adult Services through a U.S. Administration on Aging grant). Helps families prepare for planned and unexpected hospital stays. <http://www.nia.nih.gov/Alzheimers/Publications/happens.htm>
5. *Medicare and Medicaid Long-Term Care Planning*, Centers for Medicare & Medicaid Services. Web-page covers long-term care choices available, paying for care, and managing changing care needs. <http://www.medicare.gov/LongTermCare/Static/Home.asp>
6. *Caring Connections*, National Hospice and Palliative Care Organization. Website that provides information on planning for end-of-life care and links to state-specific advance directive forms. <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>

## Understanding Decision-making Capacity for Care Planning and Resource Allocation

As memory, language, and judgment abilities change, a person with Alzheimer's disease or a related dementia will lose the capacity for decision making and managing financial affairs. The following resources will assist in addressing a person with dementia's declining capacity to participate in decisions.

1. *Decision Making and Dementia*, Hartford Institute for Geriatric Nursing. Part of the Try This® series of tip sheets for hospital nurses, provides an overview of guiding principles and specific guidelines for evaluating decision-making capacity.  
[http://consultgerim.org/uploads/File/trythis/try\\_this\\_d9.pdf](http://consultgerim.org/uploads/File/trythis/try_this_d9.pdf)
2. *Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists*, American Bar Association Commission on Law and Aging and American Psychological Association. Reviews psychological assessment of six civil capacities of particular importance to older adults including medical consent capacity, sexual consent capacity, financial capacity, testamentary capacity, capacity to drive, and capacity to live independently. In addition, this handbook addresses undue influence and emerging areas such as capacity to mediate, capacity to participate in research, and capacity to vote. Mediation is a form of alternative dispute resolution that provides a way for resolving disputes between two or more parties.  
<http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf>
3. *Making Medical Decisions for Someone Else: A How-To Guide*, American Bar Association Commission on Law and Aging. A guide for consumers that discusses the role of health care proxies, importance of advance planning, steps to follow in making medical decisions, working within the health care system, resolving disputes, and situations often faced by proxies.  
[http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011\\_aging\\_bk\\_proxy\\_guide\\_gen.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_bk_proxy_guide_gen.authcheckdam.pdf)
4. *Elder Investment Fraud and Financial Exploitation Clinician Pocket Guide and Patient Brochure*, Investor Protection Trust. Resource developed through the Elder Investment Fraud and Financial Exploitation Prevention Program that seeks to educate medical professionals about how to spot older Americans who may be particularly vulnerable to financial abuse, particularly those with mild cognitive impairment, and then to refer suspected investment fraud involving these at-risk patients to state securities regulators or to local Adult Protective Services professionals.
  - Clinician Pocket Guide  
[http://www.investorprotection.org/downloads/pdf/learn/research/EIFFE\\_Clinicians\\_Pocket\\_Guide\\_National.pdf](http://www.investorprotection.org/downloads/pdf/learn/research/EIFFE_Clinicians_Pocket_Guide_National.pdf)
  - Patient Brochure  
[http://www.investorprotection.org/downloads/pdf/learn/research/EIFFE\\_Patient\\_Brochure\\_National.pdf](http://www.investorprotection.org/downloads/pdf/learn/research/EIFFE_Patient_Brochure_National.pdf)

### **Services Capable of Meeting the Unique Needs of Persons with Dementia and Caregivers**

Assistance to help persons with dementia and their caregivers identify, choose, and obtain services and supports is provided by various agencies, organizations, and other entities, including Aging and Disability Resource Centers (ADRCs) and Area Agencies on Aging (AAAs). Many of these entities partner with other organizations and agencies.

## Support Resources for Persons with Early Stage Alzheimer's Disease or a Related Disorder

1. *Early Alzheimer's disease: clinical practice guideline, number 19, consumer version*, Agency for Health Care Research and Quality. Presents information for persons with dementia, family members, and other caregivers including signs and symptoms, the need to consult a doctor, the steps involved in a comprehensive evaluation, treatable causes, getting the right care, and additional support resources.  
<http://www.ahepr.gov/clinic/alzcons.htm>
2. *Taking Action: A personal and practical guide for persons with mild cognitive impairment and early Alzheimer's disease*, Alzheimer's Association, Colorado; Minnesota Board on Aging and Alzheimer's Association, Minnesota/North Dakota. A workbook for persons with mild cognitive impairment or early Alzheimer's disease that addresses common concerns, educational information, and perspectives of people living with memory loss. This workbook can be used alone or with family and friends. Development was supported in part by an Administration on Aging grant.  
[http://www.alz.org/mnnd/documents/2010\\_Taking\\_Action\\_e-book\(1\).pdf](http://www.alz.org/mnnd/documents/2010_Taking_Action_e-book(1).pdf)
3. *Living Well Workbook*, Alzheimer's Association Minnesota-North Dakota Chapter, HealthPartners Center for Dementia and Alzheimer's Care and the Center for Spirituality and Healing at the University of Minnesota. Workbook presents brain wellness strategies and offers an opportunity to explore lifestyle changes that could lower the impact of disease symptoms and improve day-to-day living. Topics include exercise, nutrition, brain exercise, and stress reduction.  
[http://www.alz.org/mnnd/documents/Alz\\_LIVING\\_WELL\\_Workbook\\_2011\\_web.pdf](http://www.alz.org/mnnd/documents/Alz_LIVING_WELL_Workbook_2011_web.pdf)
4. *What Happens Next? A booklet about being diagnosed with Alzheimer's disease or a related disorder*, Alzheimer's Disease Education and Referral Center, National Institute on Aging. Developed by the early-stage support group at the Northwestern University Alzheimer's Disease Center. Early-stage individuals share their firsthand views about diagnosis, what to expect, how to talk with others about the disease, ways to cope in order to help others who also are facing the beginning stages of dementia, and available resources.  
<http://www.nia.nih.gov/Alzheimers/Publications/WhatHappensNext.htm#foreword>
5. *Fact Sheet for early stage persons and their family members*, Family Caregiver Alliance. Includes information on managing transitions, coping, and helpful resources.  
[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=571](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=571)
6. *Perspectives—a newsletter for individuals with Alzheimer's or a related disorder*, University of California, San Diego Shiley-Marcos Alzheimer's Disease Research Center. A quarterly publication that provides up-to-date information on relevant topics, research, and resources, and provides a forum for personal essays and reflections from persons with early-stage dementia around the world. Available free of charge by e-mail subscription. Contact Lisa Snyder, LCSW at [lsnyder@ucsd.edu](mailto:lsnyder@ucsd.edu) to request a subscription or call 858-622-5800.

7. *Early Stage Support Resources*, Alzheimer's Association. Include support groups and education programs through the local area chapter with information available at the chapter website under Find Us at <http://www.alz.org/apps/findus.asp> and the online support community at [http://www.alz.org/living\\_with\\_alzheimers\\_message\\_boards\\_lwa.asp](http://www.alz.org/living_with_alzheimers_message_boards_lwa.asp)

## Caregiver Support Resources

1. *Caregiver Guide*, National Institute on Aging. Provides caregiver tips on communication, personal care, home safety, driving, coping with holidays, visiting the doctor, and other topics. <http://www.nia.nih.gov/Alzheimers/Publications/caregiverguide.htm>
2. *Caregiver Tips*, ElderCare Locator. Provides tips, information, and a variety of suggestions shared by caregivers with caregivers. [http://www.eldercare.gov/ELDERCARE.NET/Public/Resources/Caregiver\\_Tips/Index.aspx](http://www.eldercare.gov/ELDERCARE.NET/Public/Resources/Caregiver_Tips/Index.aspx)
3. *Caregiver's Guide to Understanding Dementia Behaviors*, Family Caregiver Alliance. Provides communication tips and explanations of behavior by people with dementia including wandering, incontinence, agitation, and other behavioral symptoms. [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=391](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=391)
4. *Caregiver Support Resources*, Alzheimer's Association. Sponsors caregiver support groups through the local area chapter with information available at the chapter website under Find Us at <http://www.alz.org/apps/findus.asp> and the online support community at [http://www.alz.org/living\\_with\\_alzheimers\\_message\\_boards\\_lwa.asp](http://www.alz.org/living_with_alzheimers_message_boards_lwa.asp)
5. *Education and Care*, Alzheimer's Foundation of America. Webpage addresses a variety of issues important to caregivers including strategies for success, communication of the diagnosis, activities of daily living, behavioral challenges, therapies, safety, and medical visits. <http://www.alzfdn.org/EducationandCare/strategiesforsuccess.html>
6. *Wait a Minute: When Anger Gets Too Much*, Project C.A.R.E., an Alzheimer's Disease Demonstration Grants to States (the earlier name for the Alzheimer's Disease Supportive Services Program), funded through the North Carolina Division of Aging and Adult Services. A pamphlet on anger management. [http://www.ncdhhs.gov/aging/ad/AngerTips\\_Pamphlet.pdf](http://www.ncdhhs.gov/aging/ad/AngerTips_Pamphlet.pdf)

## Resources for Diverse and Underserved Persons with Dementia and Caregivers

1. *Diversity Portals*, Alzheimer's Association. Includes resources on dementia-related topics for individuals with dementia, families, and professionals in several languages. Topics covered include an overview of Alzheimer's disease and related disorders, signs and symptoms of Alzheimer's disease, and caregiving tips.
  - Black/African American Online Portal <http://www.alz.org/africanamerican/>
  - Latino Online Portal <http://www.alz.org/espanol/overview-espanol.asp>

- Chinese Online Portal <http://www.alz.org/asian/chinese.asp>
  - Korean Online Portal <http://www.alz.org/asian/korean.asp>
  - Vietnamese Online Portal <http://www.alz.org/asian/vietnamese.asp>
  - Interactive Brain Tour explains how the brain works and how Alzheimer’s affects the brain. Available in English and 14 other languages.  
[http://www.alz.org/alzheimers\\_disease\\_4719.asp](http://www.alz.org/alzheimers_disease_4719.asp)
2. *Alzheimer’s Caregivers—Multiple Languages*, MedLine Plus, U.S. National Library of Medicine. Web resource that discusses caregiver concerns in Chinese (simplified), Chinese (traditional), Spanish, and English.  
<http://www.nlm.nih.gov/medlineplus/languages/alzheimerscaregivers.html>
  3. *Caregiving in Indian Country: Conversations with Family Caregivers*, Centers for Disease Control and Prevention in collaboration with the National Association of Chronic Disease Directors. Issue brief that addresses issues of caring for Native Americans with dementia. <http://www.chronicdisease.org/nacdd-initiatives/healthy-aging/meeting-records/critical-issue-briefs>
  4. *Planning with Purpose: Legal Basics for LGBT Elders*, National Center for Lesbian Rights. Guide provides basic information about select areas of law that are important to lesbian, gay, bisexual, and transgender (LGBT) elders such as relationship recognition, finances, health care and long-term care.  
[http://www.nclrights.org/site/DocServer/PlanningWithPurpose\\_Web.pdf?docID=6121](http://www.nclrights.org/site/DocServer/PlanningWithPurpose_Web.pdf?docID=6121)

## Safety Resources

Alzheimer’s and other dementias cause impairments, such as impairments in balance and mobility, judgment, sense of time and place, orientation and recognition of environmental cues, and changes in vision or hearing that can reduce an individual’s ability to remain safe at home.

## Challenging Behaviors and Wandering

1. *Understanding How AD Changes People—Challenges and Coping Strategies*, Alzheimer’s Disease Education & Referral Center, U.S. National Institutes of Health. Webpage describes changes in communication skills, personality, and behavior and addresses specific issues such as wandering and safety.  
<http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/caregiving/understanding.htm>
2. *Wandering Behavior: Preparing for It and Preventing It*, Alzheimer’s Association. Provides tips for caregivers to prepare for and prevent wandering behavior.  
[http://www.alz.org/national/documents/topicsheet\\_wandering.pdf](http://www.alz.org/national/documents/topicsheet_wandering.pdf)

## Driving

1. *Dementia and Driving Resource Center*, Alzheimer's Association. Created with support from a grant from the Department of Transportation National Highway Traffic Safety Administration. The website includes four different videos depicting families having a conversation about driving by a person with dementia, links to alternative driving resources, tips on recognizing when driving is no longer safe, how to obtain a driving evaluation, and other resources.  
[http://www.alz.org/safetycenter/we\\_can\\_help\\_safety\\_driving.asp](http://www.alz.org/safetycenter/we_can_help_safety_driving.asp)
2. *Dementia and Driving*, The Hartford Insurance. A comprehensive website that includes strategies for families for discussing driving by persons with dementia and different methods of determining when to cease driving. <http://hartfordauto.thehartford.com/Safe-Driving/Car-Safety/Older-Driver-Safety/Dementia-Activity/>
3. *Dementia and Driving*, MedLine Plus, U.S. National Library of Medicine. Addresses signs that driving may no longer be safe and the steps to take.  
<http://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000028.htm>

## Falls

1. *Falls Checklist*, Centers for Disease Control and Prevention. Provides information on falls hazards in each room of the home, ways to address the problem, and tips for preventing falls.  
[http://www.cdc.gov/HomeandRecreationalSafety/pubs/English/booklet\\_Eng\\_desktop-a.pdf](http://www.cdc.gov/HomeandRecreationalSafety/pubs/English/booklet_Eng_desktop-a.pdf)
2. *Dementia Care Practice Recommendations for Professionals Working in a Home Setting*, Alzheimer's Association. Contains a chapter on falls (pages 32–36) that identifies dementia-specific issues, care goals, recommended practices and environmental approaches. [http://www.alz.org/national/documents/brochure\\_DCPRphases1n2.pdf](http://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf)

## Home Safety

1. *Home Safety for People with Alzheimer's Disease*, National Institute on Aging, U.S. National Institutes on Health. Provides information on general safety concerns, home safety throughout the home, responding to unsafe behaviors, driving, and evaluating when a person with dementia can be left home alone. A Spanish version of publication is available. <http://www.nia.nih.gov/Alzheimers/Publications/homesafety>
2. *Dementia: Keeping Safe in the Home*, MedLine Plus, U.S. National Library of Medicine. Provides safety tips for the home including falls prevention, kitchen safety, and management of wandering.  
<http://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000031.htm>

## Medication Management

1. *HomeMeds, U.S. Administration on Aging Evidence-Based Healthy Aging Program.* Program to reduce falls, dizziness, confusion, and other medication-related problems for elders living at home. Care managers use software and a pharmacist consultant to screen their clients' medications for potentially harmful problems and bring these problems to the attention of their physicians. <http://www.homemeds.org/>
2. *Get Connected! Linking Older Adults with Medication, Alcohol and Mental Health Resources,* Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. A toolkit for aging services providers to increase awareness of alcohol and medication misuse and mental health issues in older adults that includes information on memory loss and dementia. <http://www.samhsa.gov/Aging/docs/GetConnectedToolkit.pdf>

## Hoarding

1. *Working with Individuals with Dementia Who Rummage and Hoard,* Cornell University. A webpage that provides a list of 15 tips to consider when working with individuals with dementia who rummage or hoard. [http://www.environmentalgeriatrics.com/home\\_safety/working\\_with.html](http://www.environmentalgeriatrics.com/home_safety/working_with.html)
2. *Compulsive Hoarding,* National Center on Elder Abuse, Administration on Aging. A webpage that provides an overview and additional resources on hoarding. [http://www.ncea.aoa.gov/Main\\_Site/Library/CANE/CANE\\_Series/CANE\\_hoarding.aspx](http://www.ncea.aoa.gov/Main_Site/Library/CANE/CANE_Series/CANE_hoarding.aspx)
3. *Clutter and Hoarding Scale,* National Study Group on Chronic Disorganization. Provides a measure of clutter and hoarding for assessing health and safety of a home. Website requires registration to receive this free tool. <http://www.nsgcd.org/resources/clutterhoardingscale.php>

## Travel

1. *Travel Guidelines for People with Dementing Illness,* University of Iowa. Provides practical tips on travel planning. <http://www.centeronaging.uiowa.edu/archive/pubs/Newest%20Versions%20-%20pdf%20format/Travel%20Guidelines.pdf>
2. *10 Tips for Traveling with Your Loved One,* Fisher Center for Alzheimer's Research Foundation. Webpage lists tips for traveling with a person with dementia, emphasizing advanced preparation to ensure a safe and enjoyable trip. <http://www.alzinfo.org/08/treatment-care/10-tips-for-traveling-with-your-loved-one>

## Disaster Planning

1. *Caring for Someone with Dementia in a Disaster,* Federal Emergency Management Agency, U.S. Department of Homeland Security. Provides tips on advance preparation and ways to manage relocation. <http://www.fema.gov/plan/prepare/dementia.shtm#2>



2. *Get Ready Now*, Federal Emergency Management Agency, U.S. Department of Homeland Security. Outlines commonsense measures older Americans can take to prepare for emergencies before they happen.  
[http://www.ready.gov/sites/default/files/documents/files/older\\_americans.pdf](http://www.ready.gov/sites/default/files/documents/files/older_americans.pdf)
3. *Resources for Emergency Housing*, Federal Emergency Management Agency, U.S. Department of Homeland Security. Includes information on Disaster Recovery Centers (DRC) that are facilities or mobile offices where people may go for information about FEMA or other disaster assistance programs, including housing assistance and rental resource information. This webpage <http://www.fema.gov/assistance/opendrcs.shtm> contains a DRC Locator:  
[http://asd.fema.gov/inter/locator/home.htm;DRCLOC\\_JSESSIONID=78F7TyjM1Ld26hdln6Bv7JfrNv5ZFBQvfcQP9Q2GFJGp9W8Tjt95!711628929!751075945](http://asd.fema.gov/inter/locator/home.htm;DRCLOC_JSESSIONID=78F7TyjM1Ld26hdln6Bv7JfrNv5ZFBQvfcQP9Q2GFJGp9W8Tjt95!711628929!751075945)
4. *Tips for First Responders*, Division of Disability and Health Policy, University of New Mexico. Offers tip sheets with information about many types of disabilities including cognitive impairment that first responders can use during emergencies as well as routine encounters. <http://cdd.unm.edu/dhpd/tipsEnglish.asp>

### **Self-Directed Services**

Many Medicaid, Older Americans Act, and state-funded programs now offer self-directed home care. Under self-directed care, the individual consumer (or the person's representative) is responsible for hiring, training, scheduling, supervising, paying, and firing the home care worker rather than an agency.

1. *Understanding Medicaid Home and Community Services: A Primer, 2010 Edition*, U.S. Department of Health and Human Services. Addresses how best to use the Medicaid program to expand the provision of home and community services to persons with disabilities of all ages. Primer emphasizes that states need to consider each individual and his or her unique needs, resources, and social, political, and economic environments.  
<http://aspe.hhs.gov/daltcp/reports/2010/primer10.htm#intro>
2. *Developing and Implementing Self-Direction Programs and Policies: A Handbook*, National Resource Center for Participant-Directed Services. A handbook for state staff in aging and disability service systems interested in designing and implementing self-direction programs. The guide includes important information on the use of representatives for those persons who lack decision-making capacity.  
<http://www.bc.edu/schools/gssw/nrcpds/tools/handbook.html>
3. *Dementia-Capable Consumer-Directed Options*, Maine Department of Health and Human Services. An ADSSP grant-funded project in Maine that seeks to improve awareness, access, and utilization of consumer-directed options for individuals with dementia and their caregivers. The project has also developed a facilitated referral protocol to connect families not eligible for state support to other services through the Aging Network. [http://www.adrc-tae.org/tiki-index.php?page=adsspprofile&grantee\\_project=ME&project\\_title=Maine%20Alzheimer](http://www.adrc-tae.org/tiki-index.php?page=adsspprofile&grantee_project=ME&project_title=Maine%20Alzheimer)

[%27s%20Innovation%20Initiative%3A%20Dementia-Capable%20Consumer%20Directed%20Options](#)

4. *Consumer-Directed, Home and Community Services for Adults with Dementia*, Alzheimer's Association. A 2007 review of home and community-based services programs in 11 states that found that older adults with cognitive impairment or dementia were permitted to participate in at least one self-directed program in each state. [http://www.alz.org/national/documents/Consumer\\_Direction\\_issue\\_brief\\_2007.pdf](http://www.alz.org/national/documents/Consumer_Direction_issue_brief_2007.pdf)
5. *Self-Directed Care Guidebook: Developing Your Program*, Division of Aging Services, Georgia Department of Human Resources. A guidebook designed to comprehensively describe the elements of a self-directed care model employed in multiple geographic locales in Georgia. The purpose is to inform prospective program developers about opportunities and potential pitfalls. [http://aging.dhr.georgia.gov/DHR-DAS/DHR-DAS\\_Publications/SelfDirectedCareGuidebook31605.pdf](http://aging.dhr.georgia.gov/DHR-DAS/DHR-DAS_Publications/SelfDirectedCareGuidebook31605.pdf)

## **Workforce Training and Tools**

Given the needs of people with dementia, special training of people working in information and referral, options counseling, and service provision is needed, but often not provided. Dementia-specific training is especially lacking at the level of home care aides, personal assistants, and other direct care workers including training of workers in self-directed programs. This section provides some professional workforce training resources and tools.

1. *Quality Care through Quality Jobs*, PHI. Outlines the essential elements of high-quality care, services, and support for people who receive long-term care and of a quality job for direct care workers in long-term care.
  - a. 9 Essential Elements of Quality Care <http://phinational.org/about/qcqi/the-9-essential-elements-of-quality-care/>
  - b. 9 Essential Elements of a Quality Job <http://phinational.org/about/qcqi/the-9-elements-of-a-quality-job/>
2. *Adult Learner-Centered Training: An Introduction for Educators in Home and Residential Care*, PHI. Discusses the principles of adult learner-centered training as a successful approach to teaching direct care workers and provides tools for making training more learner-centered. <http://phinational.org/wp-content/uploads/2008/11/alct-guide-11-17-08.pdf>
3. *Knowledge and Skills Needed for Dementia Care: A Guide for Direct Care Workers in Everyday Language*, Michigan Dementia Care Coalition. Addresses competencies for direct care workers including knowledge of dementia disorders, person-centered care, care interactions, understanding behaviors, interacting with families, and provider self-care. <http://www.dementiacoalition.org/pdfs/DemCompGuideEverydayLang.pdf>
4. *Developing Meaningful Connections with People with Dementia: A Training Manual*, Michigan Dementia Care Coalition. Provides a foundation for training in dementia that

addresses the seven domains of competency that are discussed in the *Knowledge and Skills Needed for Dementia Care: A Guide for Direct Care Workers in Everyday Language*. <http://www.dementiacoalition.org/professionals/pdfs/Train-the-Trainer-Dementia-Care-Manual.pdf>. CD and DVD for training are available free of charge. For more information, please contact Marci Cameron at [cameronm@michigan.gov](mailto:cameronm@michigan.gov) or 517-335-0226)

5. *AlzPossible.org*, Virginia Alzheimer's Disease and Related Disorders Commission. Website developed as a "Virtual Alzheimer's Disease Center" that supports effective interventions to maintain or extend the independent functioning of people with Alzheimer's disease. The website contains links to webinars, resources, and the annual report. <http://www.AlzPossible.org>
6. *Alzheimer's Disease and Dementia Resources*, Wisconsin Department of Health Services. Website offers a variety of tools for providers and professionals in long-term care settings and dementia care at home. Many of these tools were developed through Alzheimer's Disease Demonstration Grants to States (the earlier name for the Alzheimer's Disease Supportive Services Program) including the Quality Home Visits Guide for Care Managers and Dementia Care at Home Planning Guide. <http://www.dhs.wisconsin.gov/aging/genage/alzfcgsp.htm>
7. *Dementia Care Training for Home Health Aides*, Alzheimer's Association, New York City Chapter. A 50-hour training provided once per week for 7 weeks at the New York City Chapter office, free of charge. Training covers a variety of topics including understanding the disease process, communication, home safety, behavior challenges, family interactions and cultural awareness. [http://www.alz.org/nyc/in\\_my\\_community\\_18370.asp](http://www.alz.org/nyc/in_my_community_18370.asp)
8. *Try This® Series*, Hartford Institute for Geriatric Nursing. Offers suggested tools for nurses and other hospital staff caring for older adults with dementia. "How to" videos are also available to demonstrate particular techniques. <http://consultgerim.org/resources>
9. *Dementia-Friendly Hospital Initiative*, Alzheimer's Association, St. Louis; Retirement Research Foundation; John A. Hartford Foundation; and Atlantic Philanthropies. A dementia-specific training program designed for hospital personnel to increase detection and treatment of ADRD in acute care settings, prevent complications from infection and malnutrition, facilitate recovery, prevent functional decline, and reduce high-risk behaviors to improve patient and staff safety. [http://journals.lww.com/alzheimerjournal/Abstract/2010/10000/Dementia\\_friendly\\_Hospitals\\_Care\\_not\\_Crisis\\_.11.aspx](http://journals.lww.com/alzheimerjournal/Abstract/2010/10000/Dementia_friendly_Hospitals_Care_not_Crisis_.11.aspx). For more information, contact Maggie Murphy-White at [Maggie.murphy-white@alz.org](mailto:Maggie.murphy-white@alz.org) or (314)801-0445.

## Quality Assurance Systems

A quality assurance system that addresses services for people with dementia would have at least three components: measures of dementia capability at both the LTSS systems level and the individual provider level, systematic and regular measurement of the experience of people

with dementia and their family caregivers to demonstrate user experience, and a process of continuous quality improvement to be used to improve services. So far, little attention has been given to developing these dementia-specific systems and implementing them on an ongoing basis.

1. *Dementia Quality of Life Outcomes Care Planning Tool*, WI Department of Health and Family Services. The tool provides a structured approach to planning for quality of life issues with people who have dementia. The guiding principles and specific information allow care providers, in collaboration with care managers and consumers, to personalize and focus planning and monitoring of care for persons with Alzheimer's disease and related dementia.

<http://www.dhs.wisconsin.gov/aging/dementia/Dementia%20Outcomes%20Care%20Plan%20Tool.pdf>