

March 2016

# Education Resources for People with Dementia and Their Family Caregivers

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RTI Project Number 0212050.035.002.002.001



## Table of Contents

Introduction.....	1
People With Dementia .....	1
Other Related Resources.....	3
Early-stage Dementia.....	3
Young-onset Dementia .....	4
Dementia Care and Dementia Training for Caregivers .....	5
Caregiver Health and Quality of Life .....	7
Stage-specific Caregiving .....	9
Long-distance Caregiving.....	9
Understanding Behavioral Symptoms .....	10
Safety .....	11
People With Intellectual and Developmental Disabilities and Dementia.....	12
Planning for Ongoing Care and Support.....	13

## Introduction

The majority of people with dementia live in the community, and most of their care is provided by family and friends. Although care for persons with dementia is similar to that for other conditions, their care providers tend to provide more extensive assistance, including hands-on personal care, higher levels of supervision, and responses to difficult behaviors such as aggression or wandering. This toolkit includes information about educational resources to assist family caregivers and people with dementia as they navigate through the stages of their condition.

This list of resources is not exhaustive, but represents a selection of resources reviewed by National Alzheimer's and Dementia Resource Center staff. The resources are available free of charge and come from a variety of sources, including government, academia, government-funded Alzheimer's disease centers, and nonprofit organizations dedicated to Alzheimer's disease and related disorders. Online access to the resources is noted in each of the accompanying descriptions. The "Other Related Resources" sections include supplemental materials that can be used to extend the learning experience.

## People with Dementia

People with Alzheimer's disease or related dementias (ARD) will experience many life changes. Although initial symptoms may not be severe, changes in memory and other cognitive skills eventually will become substantial enough to affect their ability to perform daily social and occupational activities. The resources provided below are designed for people with ARD and include, but are not limited to, ideas on how to tell people about the diagnosis, the importance of maintaining brain health, what to expect over time, how to work with medical professionals, and planning for the future.

- Alzheimer's Disease Tool Kit, Eastern Pennsylvania-Delaware Geriatric Education Center. [http://epadgcec.jefferson.edu/pdfs/EPaDGEC\\_ADToolkit.pdf](http://epadgcec.jefferson.edu/pdfs/EPaDGEC_ADToolkit.pdf)  
This kit contains information, education, and resources on dementia. The material is for a wide audience, which includes practitioners, patients, caregivers, and the community. (PDF)
- Brain Health as You Age: You Can Make a Difference, Administration for Community Living. [http://acl.gov/Get\\_Help/BrainHealth/docs/BrainHealthPresentation.pptx](http://acl.gov/Get_Help/BrainHealth/docs/BrainHealthPresentation.pptx)  
This presentation provides basic information related to brain health, including age-related changes in learning and memory, risks and threats to brain health, how lifestyle affects brain health, and what to do to protect brain health. (Power Point)
- I Have Alzheimer's Disease, Alzheimer's Association. <http://www.alz.org/i-have-alz/i-have-alzheimers-dementia.asp>  
This web page provides information for those recently diagnosed with Alzheimer's disease. Several topic areas can be accessed from the main page including what to expect after diagnosis, treatments and research, programs and supports, planning for the future, overcoming stigma, young onset of dementia, and how to live well with Alzheimer's disease. (Web page)

- Knowing What to Expect—<http://www.alz.org/i-have-alz/know-what-to-expect.asp>
- Treatment and Research—<http://www.alz.org/i-have-alz/treatments-and-research.asp>
- Programs and Support—<http://www.alz.org/i-have-alz/programs-and-support.asp>
- Plan for Your Future—<http://www.alz.org/i-have-alz/plan-for-your-future.asp>
- Overcoming Stigma—<http://www.alz.org/i-have-alz/overcoming-stigma.asp>
- If You Have Younger-Onset Alzheimer’s Disease—<http://www.alz.org/i-have-alz/if-you-have-younger-onset-alzheimers.asp>
- Live Well—<http://www.alz.org/i-have-alz/live-well.asp>
- Living With Alzheimer’s Disease, American Occupational Therapy Association.  
Occupational therapy practitioners help people with Alzheimer’s disease and their caregivers adapt their environment and focus on what can be done to maximize engagement in activity, promote safety, and enhance quality of life. Tips for assisting a person with dementia from an occupational therapy viewpoint are included. The tips are in English and Spanish. (PDF)
  - English: <http://www.aota.org/-/media/Corporate/Files/AboutOT/consumers/Adults/Alzheimers/Alzheimers%20tip%20sheet%20%282%29.pdf>
  - Spanish: <http://www.aota.org/-/media/Corporate/Files/AboutOT/consumers/Adults/Alzheimers/Alzheimers-Spanish-tip-sheet.pdf>
- People With Dementia, Alzheimer’s Disease International.  
<http://www.alz.co.uk/icaniwill/library/people-with-dementia>  
This web page includes information for people with dementia to assist them in a variety of areas, such as communicating with doctors, getting a diagnosis, living with memory loss, and tips for daily life. Information included on the web page is from people with dementia. (E-book)
  - Dealing with doctors and other medical professionals—<http://www.alz.co.uk/icaniwill/library/people-with-dementia/doctors>
  - Getting a diagnosis—<http://www.alz.co.uk/icaniwill/library/people-with-dementia/diagnosis>
  - Going against the stigma—<http://www.alz.co.uk/icaniwill/library/people-with-dementia/stigma>
  - Living with memory loss—<http://www.alz.co.uk/icaniwill/library/people-with-dementia/living-with-early-memory-loss>
  - Raise public awareness—[http://www.alz.co.uk/icaniwill/library/people-with-dementia/raise\\_awareness](http://www.alz.co.uk/icaniwill/library/people-with-dementia/raise_awareness)
  - Relationships and socializing—<http://www.alz.co.uk/icaniwill/library/people-with-dementia/relationships-socializing>
  - Tips for daily living—<http://www.alz.co.uk/icaniwill/library/people-with-dementia/daily-living>

- Perspectives, University of California, San Diego Shiley-Marcos Alzheimer's Disease Research Center. <http://adrc.ucsd.edu/news.html>

*Perspectives* is a quarterly newsletter for individuals with Alzheimer's or a related memory disorder. This publication 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.

### ***Other Related Resources***

- ALZConnected<sup>®</sup>, Alzheimer's Association. <https://www.alzconnected.org/>  
ALZConnected is a free online community for those affected by Alzheimer's disease or another dementia. (Interactive website)

### ***Early-stage Alzheimer's disease or a Related Dementia***

People in the early stages of ADRD may experience a number of changes with their daily life, such as difficulty remembering information, challenges completing tasks that previously were part of their regular activities, or confusion about time or location. During the early stage of ADRD, people can usually participate in their care decisions and make many other decisions related to their daily life. Before the disease progresses, it is useful to make financial, legal, and health care plans.

- If You Have Alzheimer's Disease, Alzheimer's Association. [http://www.alz.org/national/documents/brochure\\_ifyouhave\\_earlystage.pdf](http://www.alz.org/national/documents/brochure_ifyouhave_earlystage.pdf)  
This packet is designed for people diagnosed with Alzheimer's disease who are in the early stage. The information focuses on answering questions related to ways to cope with Alzheimer's disease, if what the person with Alzheimer's disease feels is normal, how they can care for themselves, what to do if they live alone, and ideas for planning for the future. (PDF)
- I Have Alzheimer's Disease, Alzheimer's Association. [http://www.alz.org/health-care-professionals/documents/newly\\_diagnosed\\_packet.pdf](http://www.alz.org/health-care-professionals/documents/newly_diagnosed_packet.pdf)  
This brochure is specifically designed for people recently diagnosed and features quotations from individuals with Alzheimer's disease. It addresses topics such as how to deal with feelings after a diagnosis, typical disease progression, treatments and research, how to share the diagnosis, changes in relationships, and planning for the future. (PDF)
- Living Well: A Guide for Persons With Mild Cognitive Impairment (MCI) & Early Dementia, Alzheimer's Association, Minnesota-North Dakota Chapter. [http://www.alz.org/mnnd/documents/15\\_ALZ\\_Living\\_Well\\_Workbook\\_Web.pdf](http://www.alz.org/mnnd/documents/15_ALZ_Living_Well_Workbook_Web.pdf)  
This workbook is for people with mild cognitive impairment and the early stage of Alzheimer's disease or another dementia. The workbook includes information on the benefits of wellness strategies as well as perspectives of people with mild cognitive impairment and early dementia and worksheets to develop a wellness plan. (PDF)

- [Taking Action: A Personal and Practical Guide for Persons with Mild Cognitive Impairment \(MCI\) and Early Alzheimer's Disease](http://www.alz.org/mnnd/documents/15_ALZ_Taking_Action_Workbook.pdf), Alzheimer's Association, Minnesota-North Dakota Chapter. [http://www.alz.org/mnnd/documents/15\\_ALZ\\_Taking\\_Action\\_Workbook.pdf](http://www.alz.org/mnnd/documents/15_ALZ_Taking_Action_Workbook.pdf)  
This workbook includes information about common concerns of people with MCI and early Alzheimer's disease, educational information, and perspectives of people living with memory loss. (PDF)
- [What Happens Next? A Booklet About Being Diagnosed With Alzheimer's Disease or a Related Disorder](https://www.nia.nih.gov/sites/default/files/84206ADEARWhatHappensNextEarlyStageBookleta_b09OCT01_0.pdf), National Institute on Aging. [https://www.nia.nih.gov/sites/default/files/84206ADEARWhatHappensNextEarlyStageBookleta\\_b09OCT01\\_0.pdf](https://www.nia.nih.gov/sites/default/files/84206ADEARWhatHappensNextEarlyStageBookleta_b09OCT01_0.pdf)  
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 to help others who also are facing the beginning stages of dementia, and available resources.

### ***Young-onset Dementia***

People with young-onset dementia experience different issues than if they were diagnosed later in life, such as raising children and disability at work. Young-onset Alzheimer's disease is rare, occurring in less than 5 percent of people with the disease. Alzheimer's disease is considered young-onset when diagnosed in a person under age 65.

- [About Young-onset Dementia](http://www.youngdementiauk.org/about-young-onset-dementia-0), Young Dementia UK. <http://www.youngdementiauk.org/about-young-onset-dementia-0>  
This web page addresses aspects of early onset of dementia and covers general topics as well as information on types of dementia in younger people, signs and symptoms, getting a diagnosis, treatment, therapies and research. Web page visitors will also find tips on living with dementia, finding support, and available resources. (Web page)
- [Early-onset Alzheimer's Disease: A Resource List](https://www.nia.nih.gov/alzheimers/early-onset-alzheimers-disease-resource-list), National Institute on Aging. <https://www.nia.nih.gov/alzheimers/early-onset-alzheimers-disease-resource-list>  
This web page provides a list of helpful resources for people diagnosed with young-onset Alzheimer's disease and their families and caregivers. The resources are organized into five categories: general resources, living with early-onset Alzheimer's, legal and financial planning, caregiving, and clinical trials and studies. (Web page)
- [Younger-onset Alzheimer's](http://www.alz.org/national/documents/brochure_earlyonset.pdf), Alzheimer's Association. [http://www.alz.org/national/documents/brochure\\_earlyonset.pdf](http://www.alz.org/national/documents/brochure_earlyonset.pdf)  
This guide is for people who have been diagnosed with younger-onset Alzheimer's disease. Persons with AD/ADRD will find information on how they can approach their diagnosis, family, friends, employment, planning for the future, and ways to focus on well-being and safety. (PDF)

## Dementia Care and Dementia Training for Caregivers

This section includes basic information about dementia and dementia care relevant to people with dementia and their caregivers. Topics addressed include understanding Alzheimer's disease and related dementias, challenges related to dementia and caregiving, as well as caregiver support. Some of the resources focus on one topic and others are more comprehensive, addressing many ADRD issues.

- About Alzheimer's Disease: Caregiving, Alzheimer's Disease Education and Referral Center, National Institute on Aging. <https://www.nia.nih.gov/alzheimers/topics/caregiving>  
This web page includes links to caregiving tip sheets and resources on issues, including behaviors, everyday care, communication, relationships, safety, caregiver health, legal and financial issues, as well as middle- and late-stage care. (Web page)
- Alzheimer's and Dementia Caregiver Center, Alzheimer's Association. <http://www.alz.org/care/overview.asp>  
This web page for caregivers includes links to information on getting daily assistance, support, and planning for the future. Each section addresses a number of issues including the stages of Alzheimer's disease and behaviors, communication, activities, respite care, caregiver health, planning ahead, care options, and safety. (Web page)
  - Stages/Behaviors—<http://www.alz.org/care/alzheimers-dementia-stages-behaviors.asp>
  - Communication and Alzheimer's—<http://www.alz.org/care/dementia-communication-tips.asp>
  - Activities—<http://www.alz.org/care/alzheimers-dementia-activities.asp>
  - Respite Care—<http://www.alz.org/care/alzheimers-dementia-caregiver-respite.asp>
  - Memory Loss and Confusion—<http://www.alz.org/care/dementia-memory-loss-problems-confusion.asp>
  - Being a Healthy Caregiver—<http://www.alz.org/care/alzheimers-dementia-healthy-caregiver.asp>
  - Planning Ahead—<http://www.alz.org/care/alzheimers-dementia-financial-legal-planning.asp>
  - Care Options—<http://www.alz.org/care/alzheimers-dementia-care-housing.asp>
  - Paying for Care—<http://www.alz.org/care/alzheimers-dementia-costs-paying-for-care.asp>
  - Safety Center—<http://www.alz.org/care/alzheimers-dementia-safety.asp>
  - Dementia and Driving Resource Center—<http://www.alz.org/care/alzheimers-dementia-and-driving.asp>
- Alzheimer's Caregiving, National Institutes of Health, Senior Health. <http://nihseniorhealth.gov/alzheimerscare/afterthediagnosis/01.html>  
This web page provides tips for caregivers on a number of issues. Quick tips and short videos related to legal and financial issues, managing medications, safety, daily activities, caring for oneself while caregiving, among other topics are found on the page. (Multimedia)

- Alzheimer's Disease or Other Dementias CARE: Changing Aging Through Research and Education<sup>®</sup>, Home Instead Senior Care.  
<http://www.helpforalzheimersfamilies.com/alzheimers-dementia-education/>

This interactive online course provides easy to use information about Alzheimer's disease and other dementias through series of videos, figures, graphics, and quizzes. (Multimedia)
- AlzOnline, Caregiver Support Online, University of Florida College of Public Health and Health Professions. <http://alzonline.php.ufl.edu/>

This reading room provides links to materials that address a range of topics including safety and injury prevention, caregiver well-being, and planning for the future. (Web page)
- Caregiver Resources, alzheimers.gov. [http://www.alzheimers.gov/caregiver\\_resources.html](http://www.alzheimers.gov/caregiver_resources.html)

The web page provides links to websites designed to assist caregivers of people with Alzheimer's disease and dementia in finding local resources and counseling and support. (Web page)
- Caregiver Resources- Alzheimer's Disease, Family Caregiver Alliance.  
<https://www.caregiver.org/health-issues/alzheimers>

This web page includes tip sheets and other resources related to caregiving for a person with Alzheimer's disease. (Web page)

  - Dementia and Driving—<https://www.caregiver.org/dementia-driving>
  - Dementia, Caregiving, and Controlling Frustration—  
<https://www.caregiver.org/dementia-caregiving-and-controlling-frustration>
  - Helping Families Make Everyday Care Choices—<https://www.caregiver.org/helping-families-make-everyday-care-choices>
  - How to Form a Support Group for Families of Brain-Impaired Adults—  
<https://www.caregiver.org/how-form-support-group-families-brain-impaired-adults>
  - Making Choices about Everyday Care (for Families)—  
<https://www.caregiver.org/making-choices-about-everyday-care-families>
- Care to Plan, University of Minnesota, School of Nursing and Center on Aging and Agency for Healthcare Research and Quality. <http://www.mcicc-connect.org/index.php>

This online tool takes about 5-10 minutes to complete and is designed to help caregivers find resources to support them caring for a person with memory loss. The tool can assist in finding resources related to education, problem solving, support groups, respite, brain health, and other related topics. (Interactive website)
- Care Training Resources: Free eLearning Workshops, Alzheimer's Association.  
<http://www.alz.org/care/alzheimers-dementia-care-training-certification.asp>

This training resource page offers a range of web-based workshops that are available to the general public, caregivers, and professionals working with individuals who have dementia. The eight web-based programs cover a wide range of topics including early detection and warning signs, general information about dementia, legal and financial planning, and information about caregiving for individuals in the early, middle, and late stages of Alzheimer's disease. Each web-based training program is approximately 1 hour in duration. (Web-based training)



- Caring for a Person With Alzheimer’s Disease, Alzheimer’s Disease Education and Referral Center, National Institute on Aging. <https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/caring-for-a-person-with-alzheimers-disease.pdf>

This is an easy-to-use guide that explains Alzheimer’s disease, how to care for someone with the disease, how caregivers can recognize when they need help. Additional important information to consider throughout all the stages of Alzheimer’s disease is also included in the guide. (PDF)

- Communication, Alzheimer’s Association. [http://www.alz.org/national/documents/brochure\\_communication.pdf](http://www.alz.org/national/documents/brochure_communication.pdf)

This brochure provides information about and recommendations to assist caregivers of people with Alzheimer’s disease on changes in communication that may occur throughout the course of the disease. (PDF)

- Dementia Caregiver Resource Guide, Connecticut Center for Healthy Aging. <https://www.hhcseniorservices.org/images/customer-files//DementiaCaregiverResourceGuide2015forweb.pdf>

This publication provides comprehensive information for caregivers on dementia, communication, understanding behaviors related to dementia, safety, activities, care options, caregiving, and legal and financial concerns. (PDF)

- Information & Support for In-Home Dementia Caregivers, U.S. Department of Veterans Affairs, Office of Rural Health. <http://www.ruralhealth.va.gov/education/dementia-caregivers/>

This website offers an educational series of 20 videos, each about 5 minutes in length. Topics addressed in the videos include an overview of dementia, communicating with doctors, caring for the caregiver, support groups, relaxation techniques, legal issues, home safety, communication, and caregiver assistance. (Video)

- Videocaregiving: A Visual Education Center for Family Caregivers, Terra Nova Films. <http://www.videocaregiving.org>

This website includes videos about caregiving for people with Alzheimer’s disease. The videos address a number of topics including how to cope with the disease, communication, driving, and activities for people with Alzheimer’s disease. (Video)

### ***Caregiver Health and Quality of Life***

Caregivers may report positive feelings about caregiving, but also may experience depression, stress related to financial issues, and declines in their own health. The resources in this section focus on physical and emotional health issues that caregivers of people with dementia may experience and various ways to address those concerns with a goal of improving quality of life.

- Alzheimer’s: How to Help a Caregiver, Mayo Clinic. <http://www.mayoclinic.org/healthy-lifestyle/caregivers/in-depth/alzheimers/art-20048212>

This web page offers suggestions on how to support the needs of family caregivers. (Web page)

- Caregiver Video Resource Center, Caregiver Action Network.  
<http://caregiveraction.org/resources/alzheimer-videos>

This website includes a selection of videos where family caregivers discuss their experience with Alzheimer's disease and dementia including signs and symptoms of Alzheimer's disease, daily experiences, caregiver tactics, and finding needed support. (Video)

- Family Carers & Friends, Alzheimer's Disease International.  
<http://www.alz.co.uk/icaniwill/library/family-carers-and-friends>

This web page provides information primarily for the family and friends of people with dementia. Information is focused on a number of issues including, how to care for the caregiver, communicate with people with dementia, and information and resources for caregivers. Information included on the web page is provided by caregivers of people with dementia. (E-book)

- Between spouses—<http://www.alz.co.uk/icaniwill/library/family-carers-and-friends/spouses>
- Caring for the caregiver—<http://www.alz.co.uk/icaniwill/library/family-carers-and-friends/care-for-caregiver>
- Communicating with people with dementia—  
<http://www.alz.co.uk/icaniwill/library/family-carers-and-friends/communication>
- Dealing with diagnosis—<http://www.alz.co.uk/icaniwill/library/family-carers-and-friends/diagnosis>
- Information and resources for family caregivers—  
<http://www.alz.co.uk/icaniwill/library/family-carers-and-friends/share-information>
- Raising awareness/dealing with stigma—<http://www.alz.co.uk/icaniwill/library/family-carers-and-friends/raise-awareness>
- Stimulation, socialization and engagement—  
<http://www.alz.co.uk/icaniwill/library/family-carers-and-friends/stimulation-socialization>
- Thoughts on being a caregiver—<http://www.alz.co.uk/icaniwill/library/thoughts-on-being-caregiver>

- iCareFamily, National Institute on Aging. [http://www.icarefamily.com/video\\_index.htm](http://www.icarefamily.com/video_index.htm)

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 coping with caregiving and improve quality of life. (Video)

- Support for Alzheimer's and Dementia Caregivers, helpguide.org.  
<http://www.helpguide.org/articles/caregiving/support-for-alzheimers-and-dementia-caregivers.htm>

This web page provides a guide for caregivers on preparing for caregiving and maintenance of emotional and physical fitness. It also offers tips on recognizing signs of and coping with caregiver stress, as well as how to make time for self-reflection, and how to support caregivers. (Web page)

- Take Care of Yourself, Alzheimer's Association.  
[http://www.alz.org/national/documents/brochure\\_caregiverstress.pdf](http://www.alz.org/national/documents/brochure_caregiverstress.pdf)  
This brochure is geared toward caregivers of those with dementia, focusing on common signs of caregiver stress and ways to manage caregiver stress. (PDF)
- Taking Care of YOU: Self-Care for Family Caregivers, Family Caregiver Alliance.  
<https://www.caregiver.org/Taking-care-you-self-care-family-caregivers>  
This web page provides information for caregivers on caring for one's own health while caring for others. This includes identifying personal barriers that may stand in the way of caring for oneself. It also includes tools on continuing self-care by learning how to reduce personal stress, set goals, communicate constructively, and seek solutions, and how to ask for and accept the help. (Web page)

### ***Stage-specific Caregiving***

Alzheimer's disease typically progresses through three stages: early, middle, and late. Although all persons diagnosed with Alzheimer's disease experience the disease differently, the symptoms generally progress from mild in the early stage to moderate in the middle stage, and finally to severe in the late stage of the disease. Caregiving tasks change as the person with dementia moves through each stage of the disease.

- Early-stage Caregiving, Alzheimer's Association.  
<http://www.alz.org/care/alzheimers-early-mild-stage-caregiving.asp>  
This web page provides information about what to expect during the early stage of Alzheimer's disease including changes in abilities related to thinking and learning, and the role of the caregiver. A list of helpful resources is also provided. (Web page)
- Middle-stage Caregiving, Alzheimer's Association. <https://www.alz.org/care/alzheimers-mid-moderate-stage-caregiving.asp>  
This web page provides information on what caregivers can expect during the middle stage of Alzheimer's disease, including changes with behavior and communication, and concerns that may arise during as the disease progresses. (Web page)
- Late-stage Care: Providing Care and Comfort During the Severe Stage of Alzheimer's Disease, Alzheimer's Association.  
[https://www.alz.org/national/documents/brochure\\_latestage.pdf](https://www.alz.org/national/documents/brochure_latestage.pdf)  
This brochure includes information on what to expect during the late stage of Alzheimer's disease, including topics related to bodily functions, food, infections, pain, and personal connection. (PDF)

### ***Long-distance Caregiving***

Many family members or other caregivers do not live in the same geographic area as the person with dementia for whom they are providing care, so some caregiving may be conducted from another city, state, or even a different country. These resources provide information on long-distance caregiving, where to find local resources, and ways a family may split up caregiving tasks among long-distance and local relatives. Some of the resources in this section

do not relate directly to Alzheimer's disease or dementia but provide information useful to anyone providing care from a long distance.

- Caregiving Resource Center: Tips for the Long-Distance Caregiver, AARP.

[http://www.aarp.org/relationships/caregiving-resource-center/info-09-2010/pc\\_tips\\_for\\_long\\_distance\\_caregiver.html](http://www.aarp.org/relationships/caregiving-resource-center/info-09-2010/pc_tips_for_long_distance_caregiver.html)

This web page provides important tips for long-distance caregivers such as creating a contact list and collecting important medical, legal, financial, and personal information. The page also provides information on how to make visits productive, find local community and online resources, and get respite care when needed. (Web page)

- Health & Aging: Long-Distance Caregiving—A Family Affair, National Institute on Aging. <https://www.nia.nih.gov/health/publication/long-distance-caregiving-family-affair>

This web page provides information for long-distance caregivers on how to offer respite and support to the primary caregiver and provide support to the aging family member from far away. (Web page)

- Health & Aging: Long-Distance Caregiving—Getting Started, National Institute on Aging. <https://www.nia.nih.gov/health/publication/long-distance-caregiving-getting-started>

This web page provides information on how to be an effective long-distance caregiver, including tips on how to provide help from far away, stay connected, and find local resources for the family member. (Web page)

- Long-Distance Caregiving, Alzheimer's Association. <https://www.alz.org/care/alzheimers-dementia-long-distance-caregiving.asp>

This web page provides quick tips and resources on topics such as assessing care needs in every stage of Alzheimer's disease, care coordination, and making the most of visits. (Web page)

- So Far Away: Twenty Questions and Answers About Long-Distance Caregiving, National Institute on Aging. [https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/so\\_far\\_away\\_twenty\\_questions\\_about\\_long-distance\\_caregiving.pdf](https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/so_far_away_twenty_questions_about_long-distance_caregiving.pdf)

This publication focuses on issues unique to long-distance caregiving and offers ideas and resources to help make long-distance caregiving more manageable. (PDF)

### ***Understanding Behavioral Symptoms***

Many people with dementia experience behavioral and psychological symptoms of dementia (BPSD), sometimes referred to as “challenging behaviors,” including depression, apathy, hallucinations, delusions, aggression, agitation, sleep disturbance, and wandering. These symptoms can be stressful for the family caregivers who are the primary source of support for most people with dementia living at home. The stresses of caring for people with BPSD may result in a loss of caregiver self-efficacy, and depression, anxiety, and cumulative health risk of the caregiver.

- Alzheimer's Behavior Management, HelpGuide.org. <http://www.helpguide.org/articles/alzheimers-dementia/alzheimers-behavior-management.htm>

This web page provides tips for caregivers on how to identify the possible cause of behavioral symptoms of Alzheimer's disease and related dementias and ways to manage these behaviors. Some of the behaviors discussed include wandering, hiding things, anger, aggression, and issues related to eating and sleep. (Web page)

- Behaviors, Alzheimer's Association.

[http://www.alz.org/national/documents/brochure\\_behaviors.pdf](http://www.alz.org/national/documents/brochure_behaviors.pdf)

This brochure provides the caregiver suggestions for responding to dementia-related behaviors such as aggression, anxiety, confusion, repetition, suspicion, wandering, and difficulties with sleep. (PDF)

- Caregiver's Guide to Understanding Dementia Behaviors, Family Caregiver Alliance.

<https://www.caregiver.org/caregivers-guide-understanding-dementia-behaviors>

This fact sheet provides practical tips on how to address behavioral and communication issues when caring for a person with dementia. Topic areas include tips on communication, and responding to behavioral symptoms such as wandering, incontinence, agitation, repetitive speech or actions, paranoia, sleeplessness, sundowning, nutrition, and bathing. (Web page)

- Challenging Behaviors, Teepa Snow. <http://teepasnow.com/resources/teepa-tips-videos/challenging-behaviors/>

This brief video provides information for providers, which is also relevant for family caregivers, on mistakes often made when faced with unexpected and different behavior from persons with dementia. The video provides strategies for determining how to work through situations when behavioral symptoms arises. (Video)

- UCLA Alzheimer's and Dementia Care Program, UCLA.

<http://dementia.uclahealth.org/body.cfm?id=68>

The web page contains seven brief video segments plus an introduction from Alzheimer's activist Patti Davis, the daughter of former U.S. President Ronald Reagan. Each video features a behavioral issue with the following general format: (1) behavior of person with dementia with the usual caregiver response; (2) expert analysis and explanation of behavior with tips to identify and eliminate triggers and suggestions for redirection; and (3) response of caregiver showing tips in action. (Multimedia)

## ***Safety***

Although Alzheimer's disease manifests differently in each person, typically as the disease progresses it becomes more difficult to keep a person with dementia safe. As the disease advances and the person with dementia's behavior and functioning continue to change, a caregiver's ability to maintain a safe environment may be challenged. It is important for caregivers to try to prevent accidents and minimize dangerous situations. In some instances, it will be necessary to adapt the home environment and other daily activities to address safety concerns.

- Home and Driving Safety Guides, The Hartford Insurance Company.

<http://www.thehartford.com/mature-market-excellence/publications-on-aging>

The Hartford Center for Mature Market Excellence has created helpful publications on a variety of topics including: family conversations about driving safety and home design ideas. Many of the publications were developed from research conducted jointly by the Center and the Massachusetts Institute of Technology AgeLab. (Web page and PDF)

- Home Safety for People with Alzheimer's Disease, Alzheimer's Disease Education and Referral Center, National Institute on Aging.

The booklet was developed for in-home caregivers of a persons with dementia to help them cope with challenges and create a safe home environment. It includes tips on identifying potential problems and hazards at home and offers solutions on how to prevent accidents. Tips on how to manage driving, planning for natural disasters and a list of resources for family caregivers are also included in the booklet. (PDF)

- English: [https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/home\\_safety\\_for\\_people\\_with\\_alzheimers\\_disease\\_2.pdf](https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/home_safety_for_people_with_alzheimers_disease_2.pdf)
- Spanish: [https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/proteccion\\_en\\_el\\_hogar\\_para\\_las\\_personas\\_con\\_la\\_enfermedad\\_de\\_alzheimer.pdf](https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/proteccion_en_el_hogar_para_las_personas_con_la_enfermedad_de_alzheimer.pdf)

- If You Care for Someone with Dementia... You are Their Advocate, University of Southern California Department of Family Medicine.

<http://www.ncea.aoa.gov/Resources/Publication/docs/Archstone-Caregiver-Brochure-Web.pdf>

This brochure provides information about elder abuse, tips for caregivers on how to protect and advocate for their loved ones. The goal of this brochure is to help family caregivers of people with dementia to learn how to take care of themselves in order to prevent mistreatment (PDF)

- This Caring Home, Weill Cornell Medical School.

<http://www.thiscaringhome.org/Index.aspx>

Users of this website can navigate through a virtual home to receive tips on home safety and enhancing quality of life for people living at home with dementia. (Interactive web page)

- Wandering Behavior: Preparing For and Preventing It, Alzheimer's Association.

[http://www.alz.org/national/documents/topicsheet\\_wandering.pdf](http://www.alz.org/national/documents/topicsheet_wandering.pdf)

This fact sheet provides information for family caregivers of people with dementia on signs of and ways to reduce wandering, as well as modifying the home environment to reduce wandering, and planning for potential issues in the future. (PDF)

### ***People with Intellectual and Developmental Disabilities and Dementia***

People with intellectual and developmental disabilities are affected by Alzheimer's disease and related disorders in some of the same ways as the general population. The additional genetic and neurological factors in people with intellectual and developmental disabilities may elevate the impact of dementia. Many of the available resources related to this topic focus specifically on Down syndrome, where the prevalence of Alzheimer's disease is high.

- A Caregiver's Guide to Down Syndrome and Alzheimer's Disease, National Down Syndrome Society. <http://www.ndss.org/Resources/Health-Care/Associated-Conditions/Alzheimers-Disease--Down-Syndrome/Anesthesia-Down-Syndrome/>

This web page includes information for families on how to manage communication and understand behavioral changes in persons with Down syndrome and Alzheimer's disease. (Web Page)

- A Caregiver's Guide to Down Syndrome and Alzheimer's Disease, Mary Hogan, MAT. <https://www.youtube.com/watch?v=QVA02p-Jhj0> (Video)  
<http://www.ndss.org/Global/Caregiver's%20Guide.Hogan.pdf> (PowerPoint)

Mary Hogan, an advocate and guardian of her late brother Bill who resided in a group home in New York State, shares her experience and insights for other family caregivers.

- Basic Questions About Adults With Intellectual/Developmental Disabilities Affected by Alzheimer's Disease or Other Dementias, NTG. <http://aadmd.org/sites/default/files/FAQ-Table-v9.pdf>

The document addresses numerous questions about Alzheimer's and related dementias in the intellectual and developmental disability community, including assessment, diagnosis, and treatment; interacting with health care providers; medications; programs, supports, and services; nutrition; and end-of-life care. (PDF)

- Caregiving for People With Dementia and Intellectual and Developmental Disabilities Including Down Syndrome, National Alzheimer's and Dementia Resource Center. [http://www.aoa.acl.gov/AoA\\_Programs/HPW/Alz\\_Grants/docs/Caregiving-Feb14-2013\\_Audio.mp3](http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/docs/Caregiving-Feb14-2013_Audio.mp3) (Audio)  
[http://www.aoa.acl.gov/AoA\\_Programs/HPW/Alz\\_Grants/docs/Caregiving-Feb14-2013-SKeller\\_Caregiving\\_for\\_people\\_with\\_dementia\\_and\\_ID-Down-syndrome.ppt](http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/docs/Caregiving-Feb14-2013-SKeller_Caregiving_for_people_with_dementia_and_ID-Down-syndrome.ppt) (PowerPoint)  
[http://www.aoa.acl.gov/AoA\\_Programs/HPW/Alz\\_Grants/docs/Caregiving-Feb14-2013-AWiatrRodriguez\\_Resources-PWD-and-ID.ppt](http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/docs/Caregiving-Feb14-2013-AWiatrRodriguez_Resources-PWD-and-ID.ppt) (PowerPoint)

Presenters discuss the impact of caring for a family member with dementia and an intellectual disability, including Down syndrome; community living providers and their work with people with dementia and intellectual disabilities, including Down syndrome; and the perspectives of a family caregiver on the challenges of caring for a family member with dementia and Down syndrome. (Audio and PowerPoint)

*Other Related Resources*

- What is Dementia? Down Syndrome, Scotland. <http://www.rrtcadd.org/resources/Technical-Assistance/Dementia-Care/Resources/whatisdementia.pdf>

A pamphlet created by Down Syndrome Scotland for adults with intellectual disabilities that explains dementia and its effects on their friends, relatives, and parents. (PDF)

### ***Planning for Ongoing Care and Support***

Ongoing care and support relates to both physical and emotional health needs and financial and legal planning. To the extent possible, persons with dementia can be involved in planning for their continued care, so long as discussions about these issues take place early on in the disease process. When decisions have not been made prior to the later stages of Alzheimer's

disease or dementia, the caregiver may benefit from guidance on how to manage making health care and other decisions.

- Alzheimer's Navigator, Alzheimer's Association. <https://www.alzheimersnavigator.org/>  
Alzheimer's Navigator provides caregivers with an interactive tool for creating a personalized action plan and linking to available community resources, supports and information. Navigator topics include working with the doctor, symptoms, safety, legal planning, knowledge, financial planning, caregiver support, care options, and daily living. (Interactive web page)
- Dementia and Alzheimer's Care: Planning and Preparing for the Road Ahead, HelpGuide.org. <http://www.helpguide.org/articles/alzheimers-dementia/dementia-and-alzheimers-care.htm>  
This web page provides tips on how to plan and prepare to care for a loved one with Alzheimer's disease and related dementia. The topics include preparing for Alzheimer's and dementia care; developing day-to-day routines; planning activities and visitors; handling challenges; considering long-term care; and evaluating an assisted living facility or nursing home. (Web page)
- Making Medical Decisions for Someone Else: A How-To Guide, The American Bar Association, Commission on Law and Aging. [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2011\\_aging\\_bk\\_proxy\\_guide\\_gen.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011_aging_bk_proxy_guide_gen.authcheckdam.pdf)  
This guide is for caregivers who serve as the health care proxy for people with dementia or others unable to make medical decisions. The guide includes information on how to prepare for being the person making health care decisions, steps to follow when making medical decisions, working within the health care system, and resolving any disputes. (PDF)

*Other Resources Related to Planning for Ongoing Care and Support (Not Specific to Alzheimer's Disease)*

- Advance Care Planning, National Hospice and Palliative Care Organization. <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3277>  
This web page provides information on advance care planning and links to additional topic areas such as how to communicate end-of-life wishes to family members, health care providers, and others, and advance directives and how to prepare them or find an agent. The website contains links to downloadable advance directives and to other brochures on this topic. (Web page and PDF)
- Consumer's Toolkit for Health Care Advanced Planning, American Bar Association. [http://www.americanbar.org/groups/law\\_aging/resources/health\\_care\\_decision\\_making/consumer\\_s\\_toolkit\\_for\\_health\\_care\\_advance\\_planning.html](http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning.html)  
This web page contains downloadable tools for health care advance planning that can be used as a complete packet or individual tools. There are 10 tools including: How to Select Your Health Care Agent or Proxy; Are Some Conditions Worse than Death; Do You Weigh Odds of Survival?; Personal Priorities and Spiritual Values Important to Your Medical Decisions; After Death Decisions to Think About Now; Conversation Scripts: Getting Past the



Resistance; The Proxy Quiz for Family & Physician; What to Do After Signing Your Health Care Advance Directive; Guide for Health Care Proxies; and Resources: Advance Planning for Health Care. (Web page and PDF)

- Financial Protection for Older Americans, Consumer Financial Protection Bureau.  
<http://www.consumerfinance.gov/older-americans/>

This web page, developed by the Office of Financial Protection for Older Americans, provides information and tools to help seniors navigate safely through financial challenges. It covers topics such as elder financial exploitation prevention and financial caregiving. The page also provides guides for agents under powers of attorney, court-appointed guardians, trustees, and Social Security agency representatives. (Web page)