

Education Resources for People Living with Dementia, Their Family Members and Other Caregivers



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Introduction

Dementia can affect various aspects of a person's life and can also impact family members and friends. Over time, changes in memory and cognition make it more difficult for a person to manage daily activities. Family and friends, rather than paid care providers, provide most of the care and support including assistance with household tasks, management of medical conditions, hands-on personal care, ongoing supervision, and responding to behavioral symptoms such as aggression or wandering. This guide includes information about open educational resources (e.g., web pages, message boards, blogs, and videos) to assist people living with dementia and family caregivers as they navigate changes in cognition and ability to manage daily activities.

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. The "Other Resources Related to Planning for Ongoing Care and Support (Not Specific to Alzheimer's Disease or Dementia)" section includes supplemental materials that are not specific to dementia.

Dementia Care Resources for People Living with Dementia and Their Caregivers

Alzheimer's disease and other dementias affect both the individual and family members. The resources in this section can be used by both people living with dementia and their caregivers to better understand the disease, what to expect as the disease progresses, the best approaches for sharing the journey, and making care decisions together.

- [Alzheimer's Disease](#) (Web page) MedlinePlus, National Library of Medicine.
This web page includes information from government and nonprofit agencies that have prepared overviews of the disease. Additionally, it links to resources on symptoms, diagnosis and tests, prevention and risk factors, treatments and therapies, living with, related issues, statistics and research, clinical trials, videos and tutorials, and materials in other languages (Spanish).
- [Alzheimer Disease information in Chinese, Korean, Japanese and Vietnamese](#) (Web page) Alzheimer's Association.

This web page provides information on Alzheimer's disease in Chinese, Korean, Japanese, and Vietnamese.

- [Basics of Alzheimer's Disease and Dementia, Alzheimer's Disease and Related Dementias](#) (Web page) National Institute on Aging, Alzheimer's Disease Education and Referral Center.

This web page links to information for consumers on Alzheimer's disease from the National Institute on Aging. The websites include resources on the basics of Alzheimer's, causes, symptoms and diagnosis, treatment, caregiving, related dementias, resources for professionals, and research and clinical trials.

- [How Alzheimer's Changes the Brain](#)
- [Alzheimer's Disease Fact Sheet](#)
- [What is Dementia?](#)
- [Types of Dementia](#)
- [Frequently Asked Questions About Alzheimer's Disease](#)
- Basics of Alzheimer's Disease and Dementia – Spanish language version is here: [Alzheimer](#)
- [Spanish Language Alzheimer's Disease Information](#) (Web page) Alzheimer's Association. This web page provides free online informational workshops in Spanish.
 - [Conozca las 10 Senales de Advertencia: La Deteccion es Importante](#)
 - [Cuerpo y Cerebro sano es Vida Sana Consejos de las Ultimas Investigaciones](#)
 - [Lo Basico la Perdida de Memoria la Demencia y la Enfermedad de Alzheimer](#)

Planning for Ongoing Care and Support

An important step for people living with dementia and their caregivers is documenting the physical and emotional health care preferences of the person living with dementia and completing financial and legal planning. People living with dementia should be involved in planning for their continued care as early in the disease process as possible, so family and friends know the person's preferences, wishes, and goals of care.

- [Legal and Financial Planning for People with Alzheimer's](#) (Web page) National Institute on Aging.

This web page has information on the need for legal and financial planning for people with Alzheimer's disease. The page is divided into sections on: legal, financial, and health care planning documents; advance directives for health care; advance directives

for financial and estate management; who can help; other advance planning advice; resources for low-income families; and a summary.

Planning for Ongoing Care and Support in People with Intellectual and Developmental Disabilities and Dementia

People living with intellectual and developmental disabilities (IDD) are affected by Alzheimer’s disease and related disorders and need to plan for their ongoing care and support to receive desired end-of-life care and have their wishes respected. People living with intellectual disabilities should not be presumed to lack capacity for making health care decisions.

- [Thinking Ahead](#) (PDFs and Videos) State of California.
This easy-to-use workbook and companion videos assist people living with developmental disabilities and their caregivers in making decisions about the end of their life. This project was funded by a Department of Developmental Services Wellness Grant and was created through the combined efforts of Alta California Regional Center, Eastern Los Angeles Regional Center, Golden Gate Regional Center, California Coalition for Compassionate Care, and the Board Resource Center. [English](#) | [Spanish](#) | [Chinese](#)
- [Thinking Ahead: My Way, My Choice, My Life at the End](#)
This video explains how to complete the workbook in three languages (English, Spanish, and Chinese).
- [Thinking Ahead: Betty & Connie Talk About Their Choices](#)
This video contains conversations with two California advocates about their personal experiences.
- [Thinking Ahead - The Importance of End of Life Planning](#)
This video gives an overview on the “Thinking Ahead” materials, with a commentary by Judy Citko, Director of the California Coalition for Compassionate Care.

Stages of Alzheimer’s Disease

Alzheimer’s disease typically progresses through three stages: early, middle, and late. Although all people 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.

- [Alzheimer’s Disease Medications Fact Sheet](#) (PDF) National Institute on Aging.
This fact sheet provides information on common medications used to treat Alzheimer’s disease. It contains a chart showing types of drugs, dosages, and common side effects.

- [Alzheimer's stages: How the disease progresses](#) (Web page) Mayo Clinic.
This web page includes information on the types of behaviors common with each stage of Alzheimer's disease and contains a statement on the rate of progression of Alzheimer's disease.

Resources for People Living with Dementia

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

- [ALZConnected](#) (Message board) Alzheimer's Association.
This is an online community and message board for people living with Alzheimer's disease or another dementia, their caregivers, family members, friends, and individuals who have lost someone to dementia to share concerns and get advice and tips from others.
- [I Have Alzheimer's Disease](#) (Web page) Alzheimer's Association.
This web page provides information for people recently diagnosed with Alzheimer's disease. Several topic areas can be accessed from the main page.
 - [Know What to Expect](#)
 - [Treatment & Research](#)
 - [Programs & Support](#)
 - [Plan for Your Future](#)
 - [Overcoming Stigma](#)
 - [Younger-Onset Alzheimer's](#)
 - [Live Well](#)
- [I Have Dementia](#), (Web page) Alzheimer's Society of Canada.
This web page for people with early memory loss is divided into various sections.
 - [Early stage](#)
 - [Self-care](#)

- [Managing changes in your abilities](#)
- [Living with Dementia: One Day at a Time!](#)
- [All about Me](#)
- [Advice from people living with Alzheimer's disease](#)
- [My Journey with Alzheimer's](#) (Blog) Pam Montana.
A personal blog written by a woman diagnosed with younger onset, early-stage Alzheimer's disease. She is an alumni member of the Alzheimer's Association National Early-Stage Advisory Group.
- [Noticing Memory Problems? What to Do Next](#) (Web page) National Institute on Aging.
This web page provides information for people with concerns about their memory and provides information on when a person should talk with a doctor. The page also contains a list of tips for dealing with forgetfulness and lists a variety of techniques that may help people stay healthy and deal with changes in their memory and mental skills.
- [WithALZmyHeart](#) (Blog) Brian Kursonis.
A blog helping people navigate an early-onset Alzheimer's diagnosis by an alumni member of the Alzheimer's Association National Early-Stage Advisory Group. Blog contains sections: Heart - blog journal and podcast; Hope - videos and articles with advice; and Mind - relevant news, and information.

Early-stage Alzheimer's Disease or a Related Dementia

People living in the early stage 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. Early on, it is important to participate in care planning and make many other decisions related to daily life. It is important to make the time for financial, legal, and health care planning.

- [The Early Stage – What to Expect](#) (Web page) Alzheimer Society of Canada.
This web page provides the person with early-stage Alzheimer's disease suggestions for how to live with this stage of memory loss and includes information on common symptoms and helpful strategies for coping.
- [I Have Alzheimer's Disease](#) (Web page) Alzheimer's Association.
This web page is specifically designed for people recently diagnosed with Alzheimer's disease and features a video message from individuals with Alzheimer's disease. The page 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.

- [Living Well: A Guide for Persons with Mild Cognitive Impairment \(MCI\) & Early Dementia \(PDF\)](#) Alzheimer's Association, Minnesota-North Dakota Chapter.

This workbook is for people living 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 and perspectives of people living with MCI and early dementia and worksheets to develop a wellness plan.

- [Taking Action: A Personal and Practical Guide for Persons with Mild Cognitive Impairment \(MCI\) and Early Alzheimer's Disease \(PDF\)](#) Alzheimer's Association, Minnesota-North Dakota Chapter.

This workbook includes information about common concerns of people living with MCI and early Alzheimer's disease, educational information, and perspectives of people living with memory loss.

Planning for Ongoing Care and Support

An important step for people living with dementia is documenting their physical and emotional health care preferences and completing financial and legal planning. People living with dementia should be involved in planning for their continued care, so family and friends know the person's preferences, wishes, and goals of care.

- [Living with Dementia: Advance Planning Guides for Persons with Dementia and Caregivers](#) (PDFs) National Alzheimer's and Dementia Resource Center.
These three guides are designed to help people living with dementia plan for future health needs, needed care and services, and how to manage money and property.

- [Health Care Planning](#)
- [Planning for Care](#)
- [Financial Planning](#)

- [Plan for Your Future](#), (Web page) Alzheimer's Association.

This web page provides information for people living with dementia to help them make legal, financial and end-of-life plans. The page is divided into four sections: emotional health care preferences and completing financial and legal planning. People living with dementia should be involved in planning for their continued care, so family and friends know the person's preferences, wishes, and goals of care.

- [Legal Planning](#)

- [Financial Planning](#)
- [Building a Care Team](#)
- [End of Life Planning](#)
- [Planning for the Future](#) (Web page) Alzheimer's Society of Canada.
This web page lists several things a person with Alzheimer's disease can do to plan for his or her future. The page is divided into sections on health and personal care planning; legal and financial planning; work, retirement, and volunteer activities; and living arrangements. There is also a link to an online [Advance Planning Workbook](#), which takes one through the steps of advance care planning.

Young-onset Alzheimer's Disease

People living with young-onset Alzheimer's disease experience different issues than people diagnosed later in life, such as issues with raising a family and disability at work. Young-onset Alzheimer's disease is rare, occurring in less than 10 percent of all people living with Alzheimer's disease. Alzheimer's disease is considered young-onset when diagnosed in a person under age 65.

- [About Young-onset Dementia](#) (Web page) Young Dementia UK.
This web page addresses aspects of early-onset dementia, covers general topics, and provides information on types of dementia in younger people, signs and symptoms, getting a diagnosis, treatment, therapies and research, and facts and figures. The web page also includes tips on living with dementia, finding support, and available resources.
 - [Make a Point About Young Onset Dementia](#)
 - [Types of Dementia in Younger People](#)
 - [Signs & Symptoms](#)
 - [Getting a Diagnosis](#)
 - [Treatment, Therapies, and Research](#)
 - [Young Onset Dementia, Facts & Figures](#)
- [Younger-onset Alzheimer's](#) (PDF) Alzheimer's Association.
This guide is for people who have been diagnosed with younger-onset Alzheimer's disease. People with 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.

Dementia Care and Dementia Training Resources for Caregivers

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

- [Alzheimer's and Dementia Caregiver Center](#) (Web page) Alzheimer's Association.
This web page for caregivers includes links to information on getting daily assistance, support, and planning for the future. Each section addresses a different issue including the stages of Alzheimer's disease and behaviors, communication, activities, respite care, caregiver health, planning ahead, care options, and safety.
 - [Stages/Behaviors](#)
 - [Communication](#)
 - [Activities](#)
 - [Respite Care](#)
 - [Memory Loss and Confusion](#)
 - [Staying Strong: Tips on Being a Health Caregiver](#)
 - [Planning Ahead](#)
 - [Care Options](#)
 - [Paying for Care](#)
 - [Safety Center](#)
 - [Dementia and Driving Resource Center](#)
- [Alzheimer's Care: Simple Tips for Daily Tasks](#) (Web page) Mayo Clinic.
This web page provides suggestions and tips for daily tasks to help a person with cognitive loss maintain a sense of independence and dignity as he or she becomes dependent on family members or caregivers.
- [Alzheimer's Caregiving, Alzheimer's Disease and Related Dementias](#) (Web page) National Institute on Aging.
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, and middle- and late-stage care.

- [Behavior Changes and Communication in Alzheimer's](#)
- [Everyday Care](#)
- [Relationships and Alzheimer's](#)
- [Safety and Alzheimer's](#)
- [Caregiver Health](#)
- [Legal and Financial Issues](#)
- [Alzheimer's Disease Tool Kit](#), (PDF) Eastern Pennsylvania-Delaware Geriatric Education Center.
This kit contains information, education, and resources on dementia. The material is for a wide audience, which includes practitioners, caregivers, and the community.
- [AlzOnline, Caregiver Support Online](#) (Web page) University of Florida College of Public Health and Health Professions.
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.
- [Care to Plan](#) (Web site) University of Minnesota, School of Nursing and Center on Aging and Agency for Healthcare Research and Quality.
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.
- [Care Training Resources: Free eLearning Workshops](#) (Web-based training) Alzheimer's Association.
This training resource page offers a range of web-based workshops that are available to the 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.

- [Caregiver Resources- Alzheimer's Disease](#) (Web page) Family Caregiver Alliance.
This web page includes tip sheets and other resources related to caregiving for a person with Alzheimer's disease.
 - [Dementia and Driving](#)
 - [Dementia, Caregiving, and Controlling Frustration](#)
 - [Guidelines for Better Communication with Brain-Impaired Adults](#)
 - [Caregiving at Home: A Guide to Community Resources](#)
 - [Caregiving at Home](#)
 - [How to Form a Support Group for Families of Brain-Impaired Adults](#)
 - [Making Choices about Everyday Care \(for Families\)](#)
- [Caregiver Tip Sheets: Keeping Home Safe](#) (Web page) Alzheimer's Greater Los Angeles.
This web page contains a series of plain language tip sheets on various topics related to Alzheimer's and related disorders, in English and Spanish.
 - [Idea! Strategy | Estrategia, Idea!](#)
 - [Anger, Frustration & Fighting | Enojo, Peleas Y Desesperacion](#)
 - [Anxiety | Ansiedad](#)
 - [Bathing | Banarse](#)
 - [Communication | Comunicacion](#)
 - [Driving | Manejando](#)
 - [Getting Lost | Perderse](#)
 - [Hallucinations | Alucinaciones](#)
 - [Keeping Home Safe | Seguridad En El Hogar](#)
 - [Medications | Medicamentos](#)
 - [Paranoia | Paranoia](#)
 - [Repeating | Repitiendo](#)
 - [Resistance | Resistencia](#)
 - [Sundowning | Cambios Al Atardecer](#)
 - [Toileting | Uso del Bano](#)

- [Communication](#) (PDF) Alzheimer's Association.
This brochure provides information about and recommendations to assist caregivers of people living with Alzheimer's disease on changes in communication that may occur throughout the course of the disease.
- [Cómo cuidar a una persona con la enfermedad de Alzheimer: Una guía fácil de usar del Instituto Nacional Sobre el Envejecimiento](#) (PDF) National Institute on Aging.
This PDF from the National Institute on Aging at NIH has helpful tips on topics including changes in behavior, wandering, healthy eating and exercise, and caregiver health.
- [Dementia, Caregiving and Transportation](#) (PDF) National Aging and Disability Transportation Center.
This publication provides transportation tips for caregivers, information on types of transportation available, dementia-friendly tips for transit drivers, items to include in a travel kit, destination cards that can be tailored for each traveler, and a list of resources.
- [Dementia Road Map for Caregivers: A Guide for Family and Care Partners](#) (PDF) Dementia Action Collaborative Washington State.
This is designed to be a “road map” of life with dementia. It provides a look at the big picture and the road ahead and offers direction and tips about what to expect, what decisions lie ahead, and what steps to take.
- [Videocaregiving: A Visual Education Center for Family Caregivers](#) (Video) Terra Nova Films.
This website includes videos about caregiving for people living with Alzheimer's disease. The videos address several topics including how to cope with the disease, communication, driving, and activities for people living with Alzheimer's disease.

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 living 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](#) (Web page) Mayo Clinic.
This web page offers suggestions on how to support the needs of family caregivers
- [Caregiver Video Resource Center](#) (Video) Caregiver Action Network.
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.

- [Going to the Hospital: Tips for Dementia Caregivers](#) (Web page) National Institute on Aging.
This web page gives tips and suggests ways to help caregivers prepare for making a visit to the emergency room or hospital. The page is separated into sections on hospital emergencies: what you can do; what to pack; before a planned hospital stay; during a hospital stay; and working with hospital staff.
- [iCareFamily](#) (Video) National Institute on Aging.
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 online training videos were created to help caregivers.
- [Living with Dementia, Caring for Someone, Quality of Life](#) (Web page) Alzheimer Society of Canada.
This web page explains factors that might affect quality of life for people living with dementia, family members, and other caregivers. It also lists some effects of caregiving on the caregiver and contains a list of suggestions to help maintain caregiver's own quality of life.
- [Tips for Alzheimer's Caregivers](#) (Web page) Helpguide.org.
This web page provides a guide for caregivers on preparing for caregiving and ways to maintain emotional and physical fitness. It also offers tips on recognizing signs of and coping with caregiver stress and how to make time for self-reflection and support caregivers.
- [Take Care of Yourself](#) (PDF) Alzheimer's Association.
This brochure is geared toward caregivers of people living with dementia, focusing on common signs of caregiver stress and ways to manage caregiver stress.
- [Taking Care of YOU: Self-Care for Family Caregivers](#) (Web page) Family Caregiver Alliance.
This web page provides information for caregivers on caring for one's own health while caring for others. The web page includes tools on continuing self-care by learning how to reduce personal stress, set goals, communicate constructively, seek solutions, and how to ask for and accept the help.

Stage-specific Caregiving

Alzheimer's disease typically progresses through three stages: early, middle, and late. Although all people 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 living with dementia moves through each stage of the disease.

- [As Dementia Progresses](#) (Web page, Videos) Alzheimer's Prevention Registry, Banner Alzheimer's Institute.
These online learning modules are designed to help caregivers understand the moderate to advanced stages of ADRD, including expected changes in memory, thinking, mood, behavior, and function. Practical strategies are described to help caregivers find success in their efforts. Other modules in the series include Compass: After the Dementia Diagnosis, Planning Ahead, and Ambiguous Loss: Living with Uncertainty.
 - [Moderate Stage Changes](#)
 - [Issues with Moderate-Stage Alzheimer's Disease](#)
 - [Goals for Treatment](#)
 - [Medications for Cognition](#)
 - [Treating Other Symptoms](#)
 - [Other Concerns – Weight Loss](#)
 - [Other Concerns – Falls](#)
 - [Other Concerns – Caregiver Well Being](#)
 - [Summary and Moving Forward](#)
- [Coping with Late-Stage Alzheimer's Disease](#) (Web page) National Institute on Aging.
This web page outlines ways for caregivers to cope with late-stage or severe Alzheimer's disease.
- [Early-stage Caregiving](#) (Web page) Alzheimer's Association.
This web page provides information about the early stage of Alzheimer's disease including how to maximize independence for the person living with dementia and the overall role of the caregiver. A list of helpful resources is also provided.
- [Middle-stage Caregiving](#) (Web page) Alzheimer's Association.
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 as the disease progresses.
- [Late-Stage Caregiving](#) (Web page) Alzheimer's Association.
This web page provides information on what caregivers can expect during the late stage

of Alzheimer's disease, including the caregiving role, care options, and changes in physical functioning for the person living with dementia.

- [Late-stage Care: Providing Care and Comfort During the Severe Stage of Alzheimer's Disease](#) (PDF) Alzheimer's Association.

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.

Long-distance Caregiving

Many family members or other caregivers do not live in the same geographic area as the person living 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: Tips for Long-Distance Caregivers](#) (Web page) Mayo Clinic.
This web page outlines some of the unique challenges in engaging in long-distance caregiving and provides tips on how to provide help to loved ones from afar and how to make the most of personal visits.
- [Family Caregiving, Care Guide: Tips for the Long-Distance Caregiver](#) (Web page) AARP.
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 creating a care team, how to make visits productive, and how to find local community and online resources and access public benefits.
- [Long-Distance Caregiving](#) (Web page) Alzheimer's Association.
This web page provides information related to assessing care needs in every stage of Alzheimer's disease, coordinating care, and making visits meaningful.
- [Long-Distance Caregiving—Getting Started with Long-Distance Caregiving](#) (Web page) National Institute on Aging.
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.

Understanding Behavioral Symptoms

Many people living 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 family caregivers, who are the primary source of support for people living with dementia living at home. The stresses of caring for people living with BPSD may result in a loss of caregiver self-efficacy, and depression, anxiety, and cumulative health risk of the caregiver.

- [Behaviors](#) (PDF) Alzheimer’s Association.
This brochure provides suggestions for caregivers on responding to dementia-related behaviors such as aggression, anxiety, confusion, repetition, suspicion, wandering, and difficulties with sleep.
- [Behavior Changes](#) (Web page) Alzheimer’s Society of Canada.
This web page provides information pages on causes of changes in behavior in people living with dementia.
 - [Managing and reducing out-of-character behavior](#)
 - [Restlessness](#)
 - [Repetitive behavior](#)
 - [Shouting and screaming](#)
 - [Walking](#)
 - [Sleep disturbance and night-time waking](#)
 - [Sundowning](#)
 - [Hiding, hoarding and losing things](#)
 - [Accusing](#)
 - [Trailing and checking](#)
 - [Losing inhibitions](#)
- [Caregiver’s Guide to Understanding Dementia Behaviors](#) (Web page) Family Caregiver Alliance.
This fact sheet provides practical tips on how to address behavioral and communication issues when caring for a person living with dementia. Topic areas include communication

and responding to behavioral symptoms such as wandering, incontinence, agitation, repetitive speech or actions, paranoia, sleeplessness, sun downing, nutrition, and bathing.

- [Challenging Behaviors](#) (Video) [Teepa Snow](#).
This brief video provides information for formal care providers, which is also relevant for family caregivers, on mistakes often made when faced with unexpected and different behavior from people living with dementia. The video provides strategies for determining how to work through situations when behavioral symptoms arises.

Safety

Although Alzheimer's disease manifests differently in each person, typically as the disease progresses it becomes more difficult to keep a person living with dementia safe. As the disease advances and the person living 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.

- [Caregiving: Adult Transportation](#) (Web page) Cleveland Clinic.
This web page lists warning signs that suggest that it is time to assess how safe it is for a person to continue driving. It also provides caregiver advice on how to talk to loved ones about driving issues and provides information on where to find transportation options in a person's local area.
- [Creating a Safe Place for Your Loved one with Dementia](#) (Web page) AARP.
This web page gives a step-by-step process on making a home safe and easier to navigate for a person living with dementia. The page also provides a link to a list of [home modifications](#), a checklist for home safety, and a list of six tips for protecting a person living with dementia.
- [Free Home and Car Safety Guides](#), (Web page and PDF) The Hartford Insurance Company.
This web page includes links to publications on a variety of home and safety topics including family conversations about driving safety and home design ideas.
- [A Guide for Families: Keeping the Person with Memory Loss Safer at Home](#) (PDF) Department of Veterans Affairs.
This booklet provides a comprehensive checklist for household safety in various rooms. There are also sections on driving; smoking, tools, and guns; and preparing for emergencies. There is a resource list which identifies some common safety items one may wish to install in the home. The booklet also contains a home safety checklist.

- [Home Safety Tips: Preparing for Alzheimer's Caregiving](#) (Web page) Mayo Clinic.
This web page lists tips to help keep people with Alzheimer's disease safe at home, including evaluating home safety and safety tips for the bathroom, kitchen, bedroom, living room, laundry room, garage, and shed and basement, and outdoor safety tips and other safety precautions.
- [Wandering Behavior: Preparing for and Preventing It](#) (PDF) Alzheimer's Association.
This fact sheet provides information for caregivers of people living with dementia on signs of and ways to reduce wandering, modify the home environment to reduce wandering, and plan for potential issues in the future.

People Living with Intellectual and Developmental Disabilities and Dementia

People living with IDD 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 living with IDD may elevate the impact of dementia. Many of the available resources related to this topic focus specifically individuals with Down syndrome, among whom the prevalence of Alzheimer's disease is high.

- [Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers](#) (PDF) National Down Syndrome Society.
This booklet is for families and caregivers and provides them with information on the connection between Down syndrome and Alzheimer's disease and suggests ways to adapt to caregiving challenges that come with the joint diagnosis.
- [Aging and Down Syndrome: A Health and Well-being Guidebook](#) (PDF) National Down Syndrome Society.
Adults with Down syndrome, along with their families and caregivers, need accurate information and education about what to anticipate as a part of growing older, so they can set the stage for successful aging. The purpose of this booklet is to help with this process and prepare families and caregivers of adults with Down syndrome for medical issues commonly encountered in adulthood, including Alzheimer's disease.
- [Aging with Intellectual and Developmental Disability Trainings, Dementia and Intellectual and Developmental Disabilities \(IDD\)](#) (Web page) University of Massachusetts Medical School, Eunice Kennedy Shriver Center.
This webinar series is an introduction to dementia as it appears in individuals with IDD and features a family caregiver experience with the disease.
 - [Introduction to Dementia and Aging with Intellectual and Developmental Disability](#)

- [Early Evaluation of Dementia and Alzheimer’s Disease](#)
- [Stages of Alzheimer’s Disease](#)
- [Applying the Knowledge to Dementia Caregiving and Caregiver Support](#)
- [Caregiving in Action: Case Studies and Practical Tips](#)
- [Basic Questions About Adults With Intellectual/Developmental Disabilities Affected by Alzheimer’s Disease or Other Dementias](#) (PDF) National Task Group on Intellectual Disabilities and Dementia Practices.
The document addresses numerous questions about Alzheimer’s and related dementias in the IDD community, including assessment, diagnosis, and treatment; interacting with health care providers; medications; programs, supports, and services; nutrition; and end-of-life care.
- [Caregiving for People with Dementia and Intellectual and Developmental Disabilities](#) Including Down Syndrome, (Audio and PowerPoint) National Alzheimer’s and Dementia Resource Center.
Presenters discuss the impact of caring for a family member living with dementia and an intellectual disability, including Down syndrome; community living providers and their work with people living with dementia and intellectual disabilities, including Down syndrome; and the perspectives of a family caregiver on the challenges of caring for a family member living with dementia and Down syndrome.
- [A Caregiver’s Guide to Down Syndrome and Alzheimer’s Disease](#) (Video) Mary Hogan, MAT.
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.
- [Intellectual Disability and Dementia: A Caregiver’s Resource Guide for Rhode Islanders](#) (PDF) Seven Hills Rhode Island and the National Task Group on Intellectual Disabilities and Dementia Practices.
This document provides informal and professional caregivers with the foundation to begin the conversation in planning supports for the individuals under their care. Some of the information is specific to Rhode Island. The resource includes sections on becoming a health care advocate; learning about screening, assessment, and diagnosis; learning about dementia; working with the health care provider; providing care; caregiver tips; getting assistance in Rhode Island; and learning more. Some local Rhode Island resources are also listed.
- [Serving People with Intellectual and Developmental Disabilities and Dementia: Online Training for Families and Persons Giving Care](#) (Web page) Minnesota Department of

Human Services.

This online training program is for family members of people living with intellectual or developmental disabilities and newly diagnosed with a type of dementia, such as Alzheimer's disease. The training provides needed resources to families to provide optimal care.

- [Welcome](#)
- [Power in Knowing](#)
- [Getting Support](#)
- [Putting Plans into Action](#)
- [Wrap-Up](#)

Planning for Ongoing Care and Support

Ongoing care and support relate to both physical and emotional health needs and financial and legal planning. To the extent possible, people living with dementia can be involved in planning for their continued care, so long as discussions about these issues takes place early 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](#) (Web page) Alzheimer's Association.
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.
- [Making Decisions for Someone with Dementia](#) (PDF) National Alzheimer's and Dementia Resource Center.
This guide is aimed at family caregivers who may have to make decisions for a person living with dementia.

Other Resources Related to Planning for Ongoing Care and Support (Not Specific to Dementia)

This section includes supplemental materials that are not specific to Alzheimer's disease or

dementia, but provides useful information related to planning for ongoing care and support as chronic conditions progress.

- [Advance Care Planning](#) (Web page and PDF) National Hospice and Palliative Care Organization.
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. The website contains links to downloadable advance directives and to other brochures on this topic.
- [Consumer's Toolkit for Health Care Advanced Planning](#) (Web page and PDF) American Bar Association.
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.
- [Financial Protection for Older Americans](#) (Web page) Consumer Financial Protection Bureau.
This web page, developed by the Office of Financial Protection for Older Americans, provides information and tools to help financial professionals, family members, and 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.
- [Making Medical Decisions for Someone Else: A How-To Guide](#) (PDF) The American Bar Association, Commission on Law and Aging.
This guide describes in simple terms what it is like to be a health care proxy, what to do while there is still time to think about it, how to make the hard decisions, and where to get help.