2016 Training Resources Compendium for Dementia Care Providers and Volunteers

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Introduction

Training is an important component for achieving dementia capability in long-term services and supports (LTSS) systems. Information and referral/assistance staff, options counselors, care managers, home care providers, other professionals, and volunteers can be trained on how to recognize and understand the unique needs of persons with dementia and their caregivers. The needs of people with dementia and their families include assistance with personal care, financial management, safety monitoring, and caregiver support. Specialized training of those providing support to individuals and families is needed, but often not provided. This toolkit includes information about trainings and training resources, knowledge tests, competencies for health care professionals, and information on state dementia training policies and state Alzheimer’s plans.

This list of resources is not exhaustive, but rather each resource was selected and reviewed by the National Alzheimer’s and Dementia Resource Center (NADRC) staff. The resources are free of charge and come from a variety of sources including government, academia, Alzheimer’s disease centers, geriatric workforce education programs, and others. Access to the resources—either online or through the NADRC—is noted in each of the accompanying descriptions. Other Related Resources sections include supplemental materials that can be used to extend the learning experience.

Basics of Dementia Care and Dementia Training Series

This section includes basic information about dementia and comprehensive dementia care training series that cover a variety of topics in dementia care including understanding Alzheimer’s disease and other dementias, behavioral symptoms, communication techniques, and caregiver support. Other resources that could be used as part of a training are also included in this section, such as video clips, tip sheets, and booklets.

- Alzheimer’s Disease and Other Dementias: Basic/Refresher Information and Current Updates for the Aging Network on Symptoms, Diagnoses and Treatments, National Institute on Aging and the Administration for Community Living (June 2012). The National Institute on Aging and Administration for Community Living, in partnership with grantees including the Alzheimer’s Association, Alzheimer’s Disease Research Centers, Alzheimer’s Disease Education and Referral Center, and the Eldercare Locator, partnered to host a webinar series to improve coordination of resources available to assist persons with Alzheimer’s Disease or other dementias and their family caregivers. This webinar features an update on symptoms, diagnoses, and treatments for Alzheimer’s disease and other dementias. (Webinar) [http://nadrc.acl.gov/node/7](http://nadrc.acl.gov/node/7)
- AlzPossible webinar series, Virginia Alzheimer’s Commission. Recorded webinars and accompanying materials are provided on a variety of topics including person centered care, behavioral symptoms, communication, individuals and families, exercise and nutrition, and home safety. (Website) [http://alzpossible.org/webinars-2/](http://alzpossible.org/webinars-2/)
• Alzheimer’s Training for Health Care Providers, University of Kentucky. This 12-module CE credit course trains health care providers, especially those in medically underserved areas, in dementia diagnosis and treatment, management, and related topics. (Web-based training) http://www.cecentral.com/dementia

• Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians, National Institute on Aging. The guide addresses the importance of cognitive assessment, benefits of early screening, and when to screen, and provides numerous resources. (Web page) https://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients#points

• Brain Health webpage, Administration for Community Living. This webpage offers evidence-based resources that can help professionals, older adults, and people with disabilities promote brain health. Educational resources are available on brain health basics, brain injury, and dementia. (Multimedia) http://acl.gov/Get_Help/BrainHealth/Index.aspx

• Care Training Resources: Free eLearning Workshops, Alzheimer’s Association. The training offers a range of web-based workshops that are available to the general public, caregivers, and professionals working with individuals who have dementia. The twelve web-based programs cover a wide range of materials including early detection and warning signs, general information about dementia, legal and financial planning, living with Alzheimer’s disease for persons with Alzheimer’s disease and for persons with younger onset, 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. The web-based training programs on early detection and general information are available in both English and Spanish. (Web-based training) http://training.alz.org/

• Caring for People with Alzheimer’s Disease: A Habilitation Training Curriculum, Alzheimer’s Association, Massachusetts/New Hampshire. This 38-page PDF provides an overview of Alzheimer’s Association, Massachusetts/New Hampshire’s 7-hour Train the Trainer curriculum, including module topics. Habilitation is the process of supplying a person with the means to develop maximum independence in activities of daily living through training or treatment. (PDF) http://www.alzmass.org/hab/

• Cognitive Impairment and Dementia: What you need to know about Alzheimer’s disease and related disorders, Alzheimer’s Association, Massachusetts and New Hampshire. This two-part training for ADRC staff was developed through collaboration between the Massachusetts ADRC and the Massachusetts and New Hampshire chapters of the Alzheimer’s Association. The training addresses, among other issues, the difficulty in balancing consumer autonomy with ensuring safety. The Administration on Aging funded the collaboration through an Alzheimer’s Disease Supportive Services Program (ADSSP) grant. (PowerPoint) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org.
• Part 1 covers the difference between dementia and Alzheimer’s disease, the effect of Alzheimer’s disease on the brain, effect on individuals with disabilities, and strategies and resources for support.

• Part 2 covers the process of assessing transitions, strategies to help the person with Alzheimer’s disease obtain the best possible care, and strategies to preserve the health and well-being of the caregiver.

• ADRC Case Study for Discussion provides a case study of a 62-year-old woman who is experiencing some changes in her cognition. The case study takes the participant through four phases of her dementia and asks discussion questions.

• Dementia Curriculum, Act on Alzheimer’s Collaborative, Minnesota. Developed by leading experts in Minnesota, the 10-module curriculum can stand on its own or be integrated into existing, complementary education. Topics addressed include disease description, demographics, societal impact, effective interactions, cognitive assessment and value of early detection, screening, disease diagnosis, quality interventions, dementia as an organizing principle of care, and caregiver support. (PowerPoint) [http://actonalz.org/dementia-curriculum](http://actonalz.org/dementia-curriculum)

• Frontotemporal Dementia, University of California, Los Angeles, 2012. In collaboration with the Los Angeles Times, the UCLA Behavioral Neurology program developed a brief video explaining frontotemporal dementia that features a son with his mother who has frontotemporal dementia. (Video) [https://www.ftd.ucla.edu/](https://www.ftd.ucla.edu/)

• Heartache and Hope: America’s Alzheimer’s Epidemic, University of California. A series of three videos addressing the financial and emotional cost of Alzheimer’s disease, developments in research, and models for Alzheimer’s disease care and caregiver support. (Video) [http://www.uctv.tv/alzheimers/](http://www.uctv.tv/alzheimers/)

• Mental Health and Aging Training Initiative webinar series, Virginia Geriatric Mental Health Partnership. The Mental Health and Aging Training Initiative delivers free education and training to enhance geriatric workforce development and improve communication and service coordination between mental health and long-term care providers. Webinars offered insight into the complex needs of older adults with behavioral health issues and provide the tools and techniques for person centered interventions using vignettes, case reviews and interactive polls. (Web-based training) [http://www.worldeventsforum.net/mhati/webinars/](http://www.worldeventsforum.net/mhati/webinars/)

• Orientation to Early Memory Loss, Alzheimer’s Association, Colorado. A 45-minute presentation on early memory loss for people with memory loss, family members, and professionals. Presentation provides an overview of changes in the brain, causes and types of dementia, warning signs, diagnostic criteria, treatment options, legal and financial planning, and practical tips for living with dementia. (PowerPoint) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org.

• Try This:® Series, Hartford Institute for Geriatric Nursing. ConsultGeriRN.org is the evidence-based geriatric clinical nursing website of The Hartford Institute for Geriatric Nursing, at New York University’s College of Nursing. Try This:® Series offers assessment tools on a variety of topics relevant to the care of older adults. The
How to Try This series is composed of articles and videos presenting cases studies demonstrating the use of the Try This.® series. The dementia series is focused on tools and strategies in the assessment of older adults with dementia. These tools can be used by a variety of health professionals. (Multimedia) https://consultgeri.org/try-this/dementia

- Working Effectively with Clients and Caregivers: A Training for ADRC staff, Wisconsin. This PowerPoint presentation for ADRC staff details caregiver statistics, evolving needs, motivational interviewing techniques, challenging situations, communication, competence, lack of insight, and agitation/aggression. (PowerPoint) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org.

Other Related Resources

- Alzheimer’s Disease Tool Kit, 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, learners, patients, caregivers, and the community. (PDF) http://epadgec.jefferson.edu/pdfs/EPaDGEC_ADToolkit.pdf

- PC P.E.A.R.L.S.: Seven Key Elements of Person-centered Care of People With Dementia in Long-term Care Homes, Alzheimer’s Society Toronto Canada. Provides links to information sheets that outline seven key elements of person-centered care for improving long-term care for people with dementia. (PDF) http://www.alzheimer.ca/en/We-can-help/Resources/For-health-care-professionals/culture-change-towards-person-centred-care/seven-key-elements-of-pcc

- UCSF Alzheimer’s Disease Center YouTube channel, University of California-San Francisco. The UCSF YouTube channel has a series of short videos on a variety of topics including the impact of dementia on memory and cognitive ability, bathing and dressing guidance for families, keeping the person safe at home, wandering and dementia, frontotemporal dementia, and loss of moral reasoning with frontotemporal dementia. (Video) https://m.youtube.com/user/UCSFMemoryandAging

Advance Planning

This section features basic information about advance planning in dementia care including assessing decision-making capacity, advance health care and financial planning, and supported decision-making. Other resources that could be used as part of a training are also included in this section, such as tip sheets, websites and articles.

- Dementia Conversations: Driving, Doctor Visits, Legal and Financial Planning, Alzheimer’s Association. This training provides tips for breaking the ice with your family so you can address some of the most common issues that are difficult to discuss: going to the doctor for a diagnosis or medical treatment, deciding when to stop driving, and making legal and financial plans for future care. (Web-based

- **Elder Investment Fraud and Financial Exploitation Prevention Program**, Investor Protection Trust. The EIFFE Prevention Program educates healthcare and legal professionals to recognize when their older clients may be vulnerable to or victims of financial abuse, particularly those patients with mild cognitive impairment, and then to refer these at-risk patients to State Securities Regulators, local adult protective services professionals or for further screening or assistance as needed. (Multimedia) [http://www.investorprotection.org/ipt-activities/?fa=iffe-pp](http://www.investorprotection.org/ipt-activities/?fa=iffe-pp)

- **Legal Issues and Alzheimer’s Disease**, Administration on Aging and the American Bar Association. Four sessions covering legal issues of people with Alzheimer’s disease and their caregivers. Persons with Alzheimer’s disease are vulnerable to financial exploitation, physical or emotional abuse, and neglect. As outlined in the National Plan to Address Alzheimer’s Disease, the webinars will help ensure that people with Alzheimer’s disease have their dignity, safety, and rights maintained.

- **Working with People with Dementia and Assessing Client Capacity**
  [http://nadrc.acl.gov/node/37](http://nadrc.acl.gov/node/37) (Webinar)

- **Advance Health Care and Financial Planning for Persons with Alzheimer’s**
  [http://nadrc.acl.gov/node/36](http://nadrc.acl.gov/node/36) (Webinar)

- **Critical Legal Issues in Alzheimer’s**
  [http://nadrc.acl.gov/node/35](http://nadrc.acl.gov/node/35) (Webinar)
  Elder Abuse, Neglect, and Exploitation and Clients with Dementia
  [http://nadrc.acl.gov/node/34](http://nadrc.acl.gov/node/34)

**Other Related Resources**

- **Decision Making and Dementia**, Hartford Institute for Geriatric Nursing. Part of the Try This® series of tip sheets for hospital nurses, provides principles and guidelines for evaluating the capacity of persons with Alzheimer’s or dementia to make their own medical decisions. (Tip sheet) [http://consultgeri.org/try-this/dementia/issue-d9.pdf](http://consultgeri.org/try-this/dementia/issue-d9.pdf)


- **Making a Plan to Manage the Disease**, U.S. Department of Health and Human Services. Plans to consider include legal and estate planning including details on guardianship, overview of legal documents and tips for finding an attorney; identification of local assistance programs; optimal living arrangements and caregiver resources for home modifications; and social security disability insurance including
Compassionate Allowance Program for early-onset Alzheimer’s. (Webpage)  
http://alzheimers.gov/planning.html

- Person Centered Care for People with Dementia: Opportunities and Challenges, National Resource Center for Supported Decision Making. This article is taken from the fall 2013 issue of ASA’s quarterly journal, Generations, an issue devoted to the topic “Integrating Services for Dual Eligibles.” (Article)  
http://supporteddecisionmaking.org/node/352

Caregiving

The majority of people with dementia live in the community and most care is provided by family and friends. Although the care provided is similar to that for other conditions, those providing care to a person with dementia tend to provide more extensive assistance, including hands-on personal care, increased supervision, and responding to difficult behaviors such as aggression or wandering. Caregivers report high levels of emotional stress and financial strain and changes in physical health (Alzheimer’s Association Alzheimer’s Disease Facts and Figures, 2014). To respond appropriately to dementia caregivers, providers need to understand their unique needs.

- Addressing the Challenges of Family Caregiving: Common Themes, ADSSP National Resource Center. (June 2013). In this audio archived presentation, Lynn Feinberg of AARP’s Public Policy Institute addresses how the caregiving role has changed over time, person and family centered care, and the top 10 caregiving themes from prominent authors of caregiving books. (Audio) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org.

- iCareFamily, 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 created online training videos to help caregivers overcome stressful situations in their caregiver role. The goal of this program is to teach skills and provide tools and resources to enhance the coping with caregiving and improve quality of life. (Video)  
http://www.icarefamily.com/video_index.htm

Other Related Resources

- Addressing Family Caregiver Needs: Policy and Practice Considerations, AARP Public Policy Institute. Fact sheet that provides an overview of the caregiver assessment process and discusses the importance of caregiver assessment in helping to maintain the health and well-being of caregivers, sustain their ability to provide care, and produce better outcomes for the care recipient. (Fact sheet)  

- Hit Pause: Helping Dementia Families Deal with Anger, Duke Family Support Program. This 10-page booklet assists professionals when providing practical help and emotional support to caregivers of people with dementia. It offers typical...
scenarios and suggested responses when helping families develop confidence in their ability to maintain balance under trying circumstances. (PDF) http://www.geri.duke.edu/service/dfsp/Hit_Pause.pdf

Diverse Populations and Dementia

The resources in this section will assist in developing a better understanding of perceptions of dementia within different cultures as a way to better respond to dementia care needs among older adults, their families, and other care providers.

- Diverse Populations, Health Disparities and Dementia, National Institute on Aging and the Administration for Community Living. The National Institute on Aging and Administration for Community Living, in partnership with grantees including the Alzheimer’s Association, Alzheimer’s Disease Research Centers, Alzheimer’s Disease Education and Referral Center, and the Eldercare Locator partnered to host a webinar series to improve coordination of resources available to assist persons with Alzheimer’s Disease or other dementias and their family caregivers. This webinar features an overview of diverse populations, health disparities, and dementia. (Webinar) http://nadrc.acl.gov/node/13

- State of the Science: Dementia Evaluation and Management Among Diverse Older Adults and Their Families, Stanford Geriatric and Education Center. This series features issues in clinical ethnogeriatrics and is targeted especially to primary care providers working with elders and their families from diverse cultural backgrounds. Fifteen webinars address a variety of topics including use of interpreters, cultural aspects of pharmacological management, and culture and home and community-based services for people with dementia. (Webinar) http://sgec.stanford.edu/video/2013-Webinars.html

Understanding Behavioral Symptoms

As dementia progresses, individuals will communicate their needs through their behavior when words become too difficult. Person-centered care requires having an understanding of the possible underlying causes of the behavioral symptoms of dementia and tailoring one’s response so that it meets individuals’ needs. Physical or emotional causes include changes in vision or hearing, dehydration, fatigue, depression, or boredom. An overstimulating environment, excessive clutter, or lack of familiarity can cause behavioral symptoms. A task that is too complicated or unfamiliar may lead to frustration and other behaviors. Applying what is known about individuals such as preferences, daily routine, hobbies, family and friends, and personal history can contribute to a meaningful response.

- Balancing Maximum Independence and Home Safety for Individuals with Dementia, Virginia Department of Aging. This webinar provides an introduction to person-centered care and aging in place, overview of dementia related disorders, and home safety issues for persons with dementia. The webinar is made available through the Virginia Alzheimer’s Disease and Related Disorders Commission statewide “Virtual

- **Challenging Behaviors, Teepa Snow.** This brief video provides information on mistakes often made when faced with unexpected and different behavior from persons with dementia, and it provides strategies for determining how to work through situations when such behavior arises. (Video) [http://teepasnow.com/resources/teepa-tips-videos/challenging-behaviors/](http://teepasnow.com/resources/teepa-tips-videos/challenging-behaviors/)

- **Dementia and Driving Resource Center, Alzheimer’s Association.** A person with dementia will eventually become unable to drive and dealing with the issue early on can help ease the transition. The Alzheimer’s Association Dementia and Driving Resource Center webpage provides videos, tips, and other resources on having the conversation, planning ahead, and signs of unsafe driving. (Multimedia) [http://www.alz.org/care/alzheimers-dementia-and-driving.asp](http://www.alz.org/care/alzheimers-dementia-and-driving.asp)

- **Management of Behavior Problems Due to Alzheimer’s Disease and Related Disorders, Minnesota Board on Aging.** This 26-page PowerPoint presentation explains the impact of behavioral symptoms for both the caregiver and individual with dementia, describes a conceptual framework for categorizing behavioral symptoms, lists the origins of behavioral symptoms, describes the steps in taking a behavioral approach to addressing behavioral symptoms, describes psychotic features related to dementia, describes pharmacologic approaches to behavioral symptoms, and lists potential causes of verbally disruptive behavior. (PowerPoint) *This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org.*

- **Person-Centered Matters, CCAL Advancing Person Centered Living.** A 16-minute video produced by the Dementia Action Alliance and filmed by a former National Geographic filmmaker. It portrays five people living with dementia and how person-centered care helps them live more fully. (Video) [http://www.ccal.org/person-centered-matters-video/](http://www.ccal.org/person-centered-matters-video/)

- **UCLA Alzheimer’s and Dementia Care Program, UCLA.** The website 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. [http://dementia.uclahealth.org/body.cfm?id=68](http://dementia.uclahealth.org/body.cfm?id=68)

**Other Related Resources**

- **Living with Alzheimer’s Disease, American Occupational Therapy Association.** Occupational therapy practitioners help people with Alzheimer’s disease and their caregivers to live life to its fullest by adapting the environment and focusing on what they can do to maximize engagement in activity (occupation), promote safety, and enhance quality of life. The tips are in English and Spanish. English: [http://www.aota.org/](http://www.aota.org/)
People with Intellectual and Developmental Disabilities and Dementia

Those with intellectual and developmental disabilities are affected by Alzheimer’s disease and related disorders in some of the same ways as the general population. However, because of the additional genetic and neurological factors, the impact of dementia may be more challenging. This section provides guides and other resources, screening tools, webinars, and video presentations for family members and caregivers. Many of the resources below focus specifically on Down syndrome.

• **Age of Change Conference**, National Down Syndrome Society and the Down Syndrome Association of Los Angeles. Over the course of the day-long conference on September 7, 2013, presenters shared information about a variety of topics relating to aging and Down syndrome. Two presentations are highlighted below:
  
  • **A Caregiver’s Guide to Down Syndrome and Alzheimer’s disease**, Mary Hogan, MAT. Mary Hogan is an advocate and was guardian for her late brother Bill who resided in a group home in New York State. She shares her experience and insights for other family caregivers.
    
    https://www.youtube.com/watch?v=QVA02p-Jhj0 (Video)
    

  • **Tips on Identifying Alzheimer’s disease in People with Down Syndrome**, Linda D. Nelson, PhD. Dr. Nelson, a research scientist on faculty in the Intellectual and Developmental Disabilities Research Institute at UCLA, addresses how to detect symptoms of dementia or atypical aging signs in people with Down syndrome. Her presentation includes Warning Signs and a Screening Tool.
    
    https://www.youtube.com/watch?v=0_5cRcAt1dg (Video)
• Caregiving for People with Dementia and Intellectual and Developmental Disabilities Including Down Syndrome, National Alzheimer’s and Dementia Resource Center. 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) http://nadrc.acl.gov/node/9

• Dementia and People with Intellectual Disabilities, New York State Developmental Disabilities Planning Council. This video describes signs of dementia and offers advice to care providers and institutions about how best to support individuals with intellectual disabilities through the stages of dementia. (Video) https://www.youtube.com/watch?v=wrKLURsAy6Y&feature=youtu.be

• Dementia Evaluation and Care in Aging Adults with IDD: Remembering Bill, National Task Group on Intellectual Disabilities and Dementia Practices project (NTG). Adults with intellectual and developmental disabilities are living longer than in the past. Functional and cognitive decline are very common social and health consequences of aging, but they are often poorly characterized and managed by health care providers and other professionals. The webinar discussion centers on the life of Bill Hogan, who was diagnosed with Alzheimer’s Disease in his mid-forties. He experienced many of the common challenges faced by individuals who develop this debilitating terminal disease. His journey is used to point out the various care issues that are faced by the individual and family, and the entire support system. Presenters are Drs. Seth Keller and Matt Janicki. (PowerPoint) http://aadmd.org/sites/default/files/Dementia_And_DD_Rememering_Bill.pdf

• Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities and Dementia, Seniors Health Knowledge Network Aging and Developmental Disabilities Community of Practice. Webinar provides a background of the NTG and an overview of the guidelines. It is approximately 1 hour in duration. (Webinar) https://www.youtube.com/watch?v=VUGK35Re7Eo

• Intellectual/Developmental Disabilities and Dementia, California. Presentation from this September 2015 webinar addresses similarities and differences in warning signs and symptoms for the general population and individuals with intellectual or developmental disabilities (IDD) with emphasis on Down syndrome, the philosophy of care, quality of life, models of care, family caregiver support, care transitions, and common IDD vocabulary. (Webinar) http://nadrc.acl.gov/node/51

• People with Intellectual or Developmental Disabilities and Dementia, National Institute on Aging and the Administration for Community Living. The National Institute on Aging and Administration for Community Living, in partnership with Alzheimer’s Association, Alzheimer’s Disease Research Centers, Alzheimer’s
Disease Education and Referral Center, and the Eldercare Locator hosted a webinar series to improve coordination of resources available to assist persons with Alzheimer’s Disease or other dementias and their family caregivers. This webinar features an update on people with intellectual or developmental disabilities and dementia. (Webinar) http://nadrc.acl.gov/node/14

- **Promising Practices in Working with People with Intellectual and Developmental Disabilities and Dementia**, National ADRC. Presentation from this February 26, 2015, webinar focuses on how to best serve the needs of people with intellectual and developmental disabilities and dementia. The presentation includes background information about the prevalence of intellectual and developmental disabilities and dementia in the United States, barriers to good dementia care for people with intellectual and developmental disabilities, and programming models for this population. Presenter for this portion of the webinar: Philip McCallion, PhD, Center for Excellence in Aging & Community Wellness, University of Albany and Mary Hogan, family advocate. (Webinar) http://nadrc.acl.gov/node/59

- **When Down Syndrome & Alzheimer’s Meet**, Arkansas Department of Human Services. In 2008, the Arkansas Department of Human Services, Division of Aging and Adult Service, was awarded an Alzheimer’s disease demonstration grant to support a project called “Bridging the Gap” to develop a DVD and book. One of the main objectives of the project was to assess the prevalence and needs of individuals in Arkansas with Down syndrome who have Alzheimer’s disease and to seek ways to better serve them and their family caregivers. Since this time, the Conway Human Development Center has continued with staff training and public education provided by Alzheimer’s Arkansas. The Conway Human Development Center is a residential treatment facility providing comprehensive services to individuals with intellectual disabilities with intensive medical or behavioral needs. This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org. (DVD and booklet)

**Screening Tools**

- **Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)**, University of Birmingham, Division of Neuroscience. Dementia screening questionnaire for individuals with intellectual disabilities developed by Shoumitro Deb, MBBS, FRCPsych, MD, Clinical Professor of Neuropsychiatry & Intellectual Disability. (PDF and abstract) http://www.birmingham.ac.uk/documents/college-les/psych/ld/lddementiascreeningquestionnaire.pdf (PDF) http://www.ncbi.nlm.nih.gov/pubmed/17470960 (abstract)

- **Early Detection Screen for Dementia (EDSD)**, National Task Group. Screening tool adapted from Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID). The purpose of the NTG-EDSD is to offer family and professional caregivers a resource to record their observations regarding changes in areas of cognitive and adaptive functioning known to be associated with dementia. This is not an instrument for the diagnosis of dementia. The intent is that caregivers will use the information captured on the NTG-EDSD to begin a dialogue with health
care practitioners and that it will serve as an aid to shared decision-making. The webpage contains links to the early detection screening tools in various languages and a manual on how to administer. (PDF) http://aadmd.org/ntg/screening

Other Related Resources

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

- **Basic Questions about Adults with Intellectual/Developmental Disabilities Affected by Alzheimer’s Disease or Other Dementias, NTG**. The document addresses questions about Alzheimer’s and related dementias; dementia and persons with intellectual disability; assessment, diagnosis, and treatment; interacting with health care providers; medications; programs, supports, and services; nutrition; and end-of-life care. (PDF) http://aadmd.org/sites/default/files/FAQ-Table-v9.pdf

- **What is Dementia? Down Syndrome, Scotland**. A pamphlet created by Down Syndrome Scotland to use with adults with intellectual disabilities that explains dementia and its effects on their friends, relatives, and parents. http://www.rrtcadd.org/resources/Technical-Assistance/Dementia-Care/Resources/whatisdementia.pdf

**People with Dementia who Live Alone**

People with Alzheimer’s and other dementias who live alone have unique care needs that vary depending on factors such as the extent of their cognitive and functional abilities, availability of a caregiver, access to adequate care and services, and coordination of care. People with dementia generally report fewer unmet care needs than their caregivers, and the number of reported unmet care needs is related to the severity of their dementia and their living situation.

Individuals with dementia living alone are vulnerable when they are unable to provide for their daily needs such as food, clothing, and shelter, or manage their own health and mental health care needs. At times, persons will resist interventions, deny or underestimate the severity and importance of their cognitive deficits, and have little or no awareness regarding their circumstances. This places them at greater risk for adverse outcomes. The provider is presented with the ethical dilemma of balancing individual autonomy and safety with the understanding that there is no perfect environment for someone with dementia living alone and that a certain amount of risk is inevitable.

- **Identifying and Meeting the Needs of Individuals with Dementia Who Live Alone, National ADRC**. Presentations from this July 30, 2015, webinar address the prevalence and characteristics of people with dementia who live alone, their unmet
care needs, signs of self-neglect and intervention strategies, and information on the experiences of persons with dementia who live alone. Presenters for this webinar: Michael Lepore, PhD, RTI International, and Phyllis “Penny” Braudy Harris, PhD, LISW, ACSW, John Carroll University. This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org. (Webinar and PowerPoint)

- **Training Curricula**, National Center on Elder Abuse. Provides numerous resources on training staff including a presentation on self-neglect and tips for training staff. [http://www.ncea.aoa.gov/Training/Curricula/index.aspx](http://www.ncea.aoa.gov/Training/Curricula/index.aspx)


**Other Related Resources**

- AlzOnline, Caregiver Support Online, University of Florida College of Public Health and Health Professions. Website features a reading room addressing a range of topics including safety and injury prevention. [http://alzonline.phhp.ufl.edu/](http://alzonline.phhp.ufl.edu/)


- Dementia Care Practice Recommendations for Professionals Working in a Home Setting, Alzheimer’s Association. Information on Making the Most of the Home Visit (for any individual with dementia) and Considerations for Those Who Live Alone can be found on pages 53-54. [https://www.alz.org/national/documents/Phase_4_Home_Care_Recs.pdf](https://www.alz.org/national/documents/Phase_4_Home_Care_Recs.pdf)

- Home and Driving Safety Guides, The Hartford Insurance Company. The Hartford Center for Mature Market Excellence has created helpful publications on topics ranging from family conversations about driving safety to home design ideas. Many were developed from research conducted jointly by the Center and the Massachusetts Institute of Technology AgeLab. [http://www.thehartford.com/mature-market-excellence/publications-on-aging](http://www.thehartford.com/mature-market-excellence/publications-on-aging)

- Preventing Elder Investment Fraud, Investor Protection Trust. Website with resources and materials including a clinicians pocket guide and a short video that addresses and
explains the widespread problem of elder investment fraud and financial exploitation and explores some of the possible solutions. The video includes interviews with elder fraud victims, their families, doctors, and caretakers in addition to representatives from the Pennsylvania Securities Commission. (Multimedia) http://www.investorprotection.org/protect-yourself/?fa=protect-seniors

- **This Caring Home**, Weill Cornell Medical School – User can navigate through a virtual home; also provides tips on home safety and enhancing quality of life for people living at home with dementia. (Multimedia) http://www.thiscaringhome.org/Index.aspx


**Dementia Capability**

Model dementia-capable Aging Network and LTSS systems are able to address the unique needs of persons with dementia who are losing their ability to communicate and care for themselves. These systems also support family caregivers who take on progressively more responsibility for managing and coping with the needs of their loved ones. When persons with dementia or a family caregiver use the Aging Network or the LTSS system, they need information and programs that are tailored to their unique needs in the areas of information and assistance, options counseling, and services.

- **Dementia Capability webinars**, Rosalynn Carter Institute. The Rosalynn Carter Institute for Caregiving has a series of Dementia Capability Webinars that can be used to train a variety of professionals, including State Units on Aging, AAA, and ADRC staff members. The intended audience is professionals serving families and individuals with dementia. The topics of the webinars vary, with an emphasis on building general knowledge about dementia. Each webinar lasts approximately 1 hour. (Webinar) http://www.rosalynncarter.org/gdas_trainings/

- **Dementia Capable Wisconsin: Dementia Care Training for Community Members**, University of Wisconsin Oshkosh Center for Career Development and Employability Training. The University of Wisconsin, Oshkosh Center for Career Development and Employability Training (CCDET) along with the Wisconsin Department of Health Services, Division of Long Term Care, has developed dementia care training specific to community members. Because most people living with dementia reside in the community, business, government, spiritual and volunteer organizations often seek additional information to learn more about how to interact with community members who are living with dementia. (Online training) https://wss.ccdet.uwosh.edu/stc/dhsdementia/psciis.dll?linkid=252034&mainmenu=DHSDEMENTIA&top_frame=1

- **Dementia Friendly Provider Practice Tools and Training Videos**, Dementia Friendly America. Website offers an array of provider practice tools and training videos under the Tools and Resources section addressing screening, diagnosis, diagnostic disclosure, and care coordination. (Website) http://www.dfamerica.org/
• No Wrong Door Dementia Capable Trainings, Virginia. As part of an ongoing Administration for Community Living grant for the Alzheimer's Disease Supportive Services Program, the Virginia Department for Aging and Rehabilitative Services is expanding and standardizing dementia knowledge within the No Wrong Door network. The webpage provides information on available virtual and written training materials for Information and Referral Specialists, Options Counselors, and Care Transition Coaches. http://www.vda.virginia.gov/alzheimers.asp

Options Counseling and other Aging and Disability Resource Center staff

The resources below focus on person-centered support and guidance to individuals, family members, and caregivers to help them develop a long-term care plan that closely aligns with their specific needs and personal preferences. The steps in the Option Counseling process include initial interview, assistance in developing a person-centered plan detailing the individual’s decisions and next steps, help locating necessary services, and a follow-up over time. This section provides resources that can be used in training options counselors and other ADRC staff.

• Aging Services and Supports for People Living with Dementia - ADRC Dementia Training, Portland State University. These web-based trainings were developed by Portland State University based on input and piloting by Oregon ADRC partners. Individuals may view these trainings on their own; however group viewing and discussion using the provided Companion Guides is encouraged. (Webinar video and PDF)

 Tier 1
  • Module 1 - Implementing Person-Centered Dementia Support
  • Module 2 - Communication and Behavioral Expression
  • Module 3 - Medical and Clinical Aspects of Dementia
  • Module 4 - Information and Referral Issues
  • Tier 1 Companion Guide (PDF, December 2014)

 Tier 2
  • Module 5 - Introducing Decision Support Tools
  • Module 6 - Decision Support through Person-Centered Planning
  • Module 7 - Decision Support in Care Transitions
  • Module 8 - Decision Support for Advanced Care and End of Life Planning
  • Tier 2 Companion Guide (PDF, November 2014)

• Addressing the Needs of Persons with Dementia through Options Counseling, ADSSP National Resource Center. In this audio archived presentation, Eric Weakly and Cathy Creapaux discuss the Administration on Aging’s standards for options counseling and approaches for implementing the options counseling standards with a
focus on creating a dementia capable system. (Audio)

• Options Counseling Family Profiles for Practice, Technical Assistance Exchange. Family scenarios that can be used to role play some challenging options counseling situations.

• Conducting Counseling Support: Role Play and Analysis provides role play situations for supervisor response. Each involves a new long-term support counselor seeking advice and counsel from his or her supervisor. A set of discussion questions is presented at the end of each role-play scenario. (PDF) http://www.adrc-tae.acl.gov/tiki-download_file.php?fileId=31009

• Options Counseling Exercise, Family Profile: Early State Dementia Challenge provides scenario of married couple in their 70s where the husband is showing signs of early-stage dementia. Exercises include worksheet for assessing needs/situation, questions to ask, identifying priorities, and establishing next steps. (PDF) http://www.adrc-tae.acl.gov/tiki-download_file.php?fileId=28160

• Person-Centered Planning: Structures for Options Counseling, University of New Hampshire Institute on Disability. A presentation from the 2011 National Meeting on Person-Centered Planning: Structures for Options Counseling by Patty Cotton from the University of New Hampshire’s Institute on Disability. It includes examples of graphic person-centered planning tools. (PowerPoint) http://www.adrc-tae.acl.gov/tiki-download_file.php?fileId=30183

Information and Referral/Assistance

Some people with dementia and their caregivers can arrange for the community services and supports they need if they are given a list of local agencies and providers. Others need more assistance to define their service needs, to select a provider that can accommodate their service needs, and to initiate the service. People with dementia need assistance with these tasks because of their cognitive impairments and caregivers may need assistance because they are overwhelmed by the necessary caregiving activities.

• Communicating with People who Have Alzheimer’s or other Dementia: Aging I&R/A Tips, National Aging Information and Referral Support Center, National Association of State Units on Aging. Tip sheet developed to assist aging information and referral staff with effective communication techniques when working with someone who has Alzheimer’s disease or another dementia. (PDF) http://www.nasuad.org/documentation/I_R/Dementia.pdf

Care Coordination/Care Management

The tools and resources contained in this section are designed to assist professionals with coordinating care, communicating with other providers, and incorporating expressed needs and preferences when providing safe, appropriate and effective care to persons with dementia.
• ADRC Decision Tree, Wisconsin. A one-page document of the ADRC of Portage County Program Decision Tree to Determine Eligibility for Administration on Aging ADSSP Direct Services. (PDF) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

• Care Management Guidelines, Chronic Care Consortium in Alzheimer’s Disease. This five-page document contains Care Management Guidelines in table form aimed at care consultants or other professionals. The table lists assessments and interventions/resources that should occur during the diagnosis/initial visit, early, middle, late, and terminal stages. (Word document) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

• 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. (PowerPoint) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

• Quality of Life Outcomes for People with Alzheimer’s Disease and Related Dementia, Care Planning Tool for Providers, 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. (PDF) https://www.dhs.wisconsin.gov/publications/p2/p23195.pdf

Other Specific Professional Audiences

The trainings listed below are targeting specific health care professionals and community leaders, including first responders, aging network and referral staff, and minority church leaders.

• Acute Hospitalization and Alzheimer’s Disease: A Special Kind of Care, National Institute on Aging. Designed to help hospital professionals to meet the needs of patients with dementia, this webpage contains links to facts about Alzheimer’s disease, communication tips, personal care techniques, suggestions for working with behaviors and environmental factors to consider in the ER and in the hospital room. (Webpage) http://www.nia.nih.gov/alzheimers/publication/acute-hospitalization-and-alzheimers-disease

• Approaching Alzheimer’s: First Responder Training Program, Alzheimer’s Association. An online training that uses an interactive format, developed with input from first responders. (Web-based training) http://www.alz.org/care/alzheimers-first-responder.asp

• Assessment and Management of Alzheimer’s Disease and Other Dementias New Jersey Geriatric Education Center (NJGEC) has a free, five-module, web-based program on dementia care. The modules cover the inter-professional approach to assessment and management of Alzheimer’s disease and dementia. The series is provided with funding from the Health Resources and Services Administration and in
collaboration with ACL. (Web-based training)  
http://www.rowan.edu/som/njisa/njisanjgec-downloadable-resources/

- **Brain Health Mini Unit**, Wisconsin Department of Public Instruction. An education tool designed to provide health educators with a short unit of instruction to aid in the understanding of the brain health with a particular focus on dementia. The curriculum is appropriate for middle school and high school students (grades 7 through 12). The mini-unit provides PowerPoint slides, videos, instructor notes, additional resources, and results from a community school pilot of the curriculum. (Multimedia)  

- **IACP Alzheimer’s Initiative**, International Association of Chiefs of Police (IACP). Funded by the Department of Justice, this website provides a variety of resources to help first responders improve their knowledge and skills to safeguard people with dementia. (Multimedia)  
http://www.theiacp.org/alzheimers

- **Laminated Pocket Card for Physicians and Other Primary Care Providers**, North Carolina. Two-page document with one-page description and actual pocket card. On one side is information on coding and billing, the other contains information on community resources, including when, how, and to whom to make referrals. (PDF)  
*This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org*

- **Primary Care Screening and Assessment**, Minnesota. This six-slide PowerPoint presentation was used in Minnesota and participants learned to list relevant screening tools used to identify possible memory loss, determine which screening tool is most applicable depending on the setting, evaluate activities of daily living and function, evaluate caregiver burden and stress, and evaluate behavioral problems related to dementia. (PowerPoint)  
*This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org*

- **Using an Interprofessional Family-Centered Approach to Dementia Care**, Eastern Pennsylvania-Delaware Geriatric Education Center. This online training module takes the interprofessional team concept to its fullest expression with the patient and family/caregiver(s) as core team members. The concept of this module is to give health care practitioners and students an understanding of an interprofessional model of dementia care. (Web-based training)  
http://epadgec.jefferson.edu/modules/dementia/

**Evidence-Based Interventions Training and Resources**

This section lists trainings and other resources that support community implementation of specific evidence-based interventions that have been rigorously tested through randomized-controlled clinical trials with results published in a peer reviewed journal. These resources were developed by ADSSP grantees implementing evidence-based interventions.

**New York University Caregiver Intervention (NYUCI)**

- **Dementia Care Coordination**, Minnesota. This 16-slide PowerPoint presentation describes the role and responsibilities of the Dementia Care Coordinator, discusses
four areas of counseling for the caregiver of the person with dementia, and outlines the Mittelman counseling model including six techniques useful in individual counseling and approaches for responding to reluctance of a caregiver to ask for help from family. (PowerPoint) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

• NYUCI Implementation Guide, ADSSP Evidence-Based Grantee Collaborative. The guide shares the experiences and lessons learned from six implementation sites funded by the Administration on Aging to translate the New York University Caregiver Intervention. This guide is intended to serve as a tool for agencies and organizations in selecting and implementing this intervention successfully. The implementation sites, located in California, Florida, Georgia, Minnesota, Utah, and Wisconsin, collaborated in the creation of this manual with the leadership of the Rosalynn Carter Institute for Caregiving. (PDF) http://www.rosalynncarter.org/UserFiles/NYUCI(1).pdf

Reducing Disability in Alzheimer’s Disease (RDAD)

• RDAD Replication Manual, Ohio Department of Aging. The RDAD Replication Manual written and produced by the Ohio RDAD Replication Project is designed to accompany the RDAD Intervention manual created by Linda Teri, PhD, University of Washington. The RDAD Replication Manual is designed for both the RDAD Trainers/clinical staff, who offer the RDAD program to families living with Alzheimer’s disease and related dementia, and Program Administrators or clinical supervisors, who administer and manage the program. (PDF) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

REACH II

• REACH II Caregiver Notebook, Florida. Through the Florida ADSSP grant, REACH II participants received a Caregiver Notebook that provided information to be used during home visits and phone calls. The notebook contains information related to memory loss and dementia as well as stress management, home safety, communicating with the doctor, getting help and planning for the future. The Caregiver Notebook is available in English and Spanish. (Word and PDF) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

Savvy Caregiver

• Creating Confident Caregivers: Personal Care Aide Training, Michigan. A three-page document detailing modification of the Savvy Caregiver Program into a shorter 3.5-hour module provided by master trainers. (Word document) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

• Everything You Wanted to Know about Dementia: A Practical Guide to Alzheimer’s Disease and Related Dementia for Associate Trainers of Maine’s Savvy Caregiver Program, Maine. A 25-page PDF providing one- to two-page reviews of myths and
facts of dementia, common questions, warning signs, other causes of mental decline, questions of diagnosing, stages of dementia, Alzheimer’s bill of rights, treatment for symptoms, alternative treatments, behavior and challenging behavior, relationship changes, family conflict in caregiving, and grief and loss in caregiver and resources. (PDF) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

• Providing Home and Community-based Supports and Services: Working with Alzheimer’s and Other Types of Dementia, Michigan. This 38-page PDF is a module from The Creating Confident Caregivers-Veterans Affairs project designed to test a compressed version of an evidence-based dementia caregiver program: Savvy Caregiver Program. The goal of the module is to increase learners’ understanding of Alzheimer’s disease/dementia and to make them more effective at their jobs. The module covers knowledge about dementia, skills assisting people with dementia, and, a confident attitude in applying skills and knowledge. (PDF) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

• Savvy Caregiver Training Manual and PowerPoint presentation, Maine. A 193-page training manual for trainers of the Savvy Caregiver Program and a 200-slide PowerPoint presentation by Ken Hepburn for training on the Savvy Caregiver program. (PowerPoint) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

Tailored Activity Program (TAP)

• The Tailored Activity Program (TAP) training and implementation materials, Kentucky. Three binders are used in training and implementing TAP. (Word) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org

• Intervention Manual: The manual is used in training and then as a reference when implementing TAP. The manual should be read in its entirety prior to the face-to-face training and then referred to thereafter.

• Documentation Binder: A documentation binder is created for each participant. It contains the materials and documentation needed for implementing the intervention with a dyad (caregiver/person with dementia) and collecting data for evaluation of the intervention.

• Caregiver Notebook: A binder is provided to each caregiver as part of the intervention. The Notebook is referred to throughout the intervention. The Notebook should be read in its entirety prior to the face-to-face training.

Knowledge Tests

Listed below are tests that can be used to assess an individuals’ knowledge of Alzheimer’s disease/dementia and the effectiveness of training programs in increasing dementia knowledge.

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• Alzheimer’s Disease Knowledge Scale (ADKS), Brian Carpenter, Steve Balsis, Poorni Otilingam, Priya Hanson, and Margaret Gatz. The Alzheimer’s Disease Knowledge Scale is a 30-item true/false scale designed for use with health care professionals, students, and the general public to assess knowledge about Alzheimer’s disease. The questions cover various topics including risk factors, symptoms, assessment and diagnosis, course of the disease, impact, caregiving, treatment, and management.

• Alzheimer’s Disease Knowledge Scale (PDF)  

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2667675/

• Evidence Reference List for Alzheimer’s Disease Knowledge Scale (PDF)  

• Knowledge about Memory Loss and Care (KAML-C), Daniel Kuhn, Scott King, and Bradley Fulton. KAML-C is a 15 multiple choice item scale designed for use with family caregivers of individuals in the early stage of Alzheimer’s disease. The questions address medical information, caregiving, and legal/financial planning. (Word document) This resource can be obtained through the NADRC by contacting Patty Yuen at pyuen@rti.org


• Rosalynn Carter Institute Webinar Knowledge Tests – Rosalynn Carter Institute. The webinars offered by the Rosalynn Carter Institute also have a knowledge test component to assess the level of dementia capability knowledge of staff members who complete the trainings. (Word) http://www.rosalynncarter.org/gdas_trainings/

Competencies for Health Care Professionals

Competencies identify the skills, knowledge, and behavior required to work effectively with a specific population. Below are competencies for health care professionals in geriatrics that include specific competencies for working with persons who have dementia.

• Geriatrics Competencies by Specialty. The Portal of Geriatrics Online Education. Many disciplines have created minimum geriatric competencies to ensure that the graduating learner provides competent care to older patients. The webpage includes Geriatrics Competencies for medical professionals, nurses, and other disciplines. (Website) http://www.pogoe.org/geriatrics-competencies

• Geriatric Social Work Competency Scale II with Lifelong Leadership Skills, Social Work Leadership Institute, Council on Social Work Education. Provides a scale for evaluating skills recognized by gerontological social workers as important to social
workers effectively working with and on behalf of older adults and their families. These competences address the different levels across the social work learning continuum, from bachelor of social work to master of social work at the core and advanced levels and in life-long learning post-MSW. (Website) http://www.cswe.org/File.aspx?id=25445

State Dementia Training Policy and Alzheimer’s Disease Plans Recommendations

To meet the needs of the growing population with Alzheimer’s disease and related dementias, the number of health care professionals specializing in dementia care and relevant training will need to increase. Many states have professional licensing requirements regarding dementia-specific training. This section addresses dementia training policy recommendations and state Alzheimer’s Disease Plans’ recommendations for workforce development and training.

• Dementia Training Requirements, Justice in Aging. Webpage provides links to state summaries of dementia training laws and regulations as well as reports on professional licensure, first responders, health settings and promising practices. http://act.alz.org/site/PageServer?pagename=dementia_training