Dementia Care:

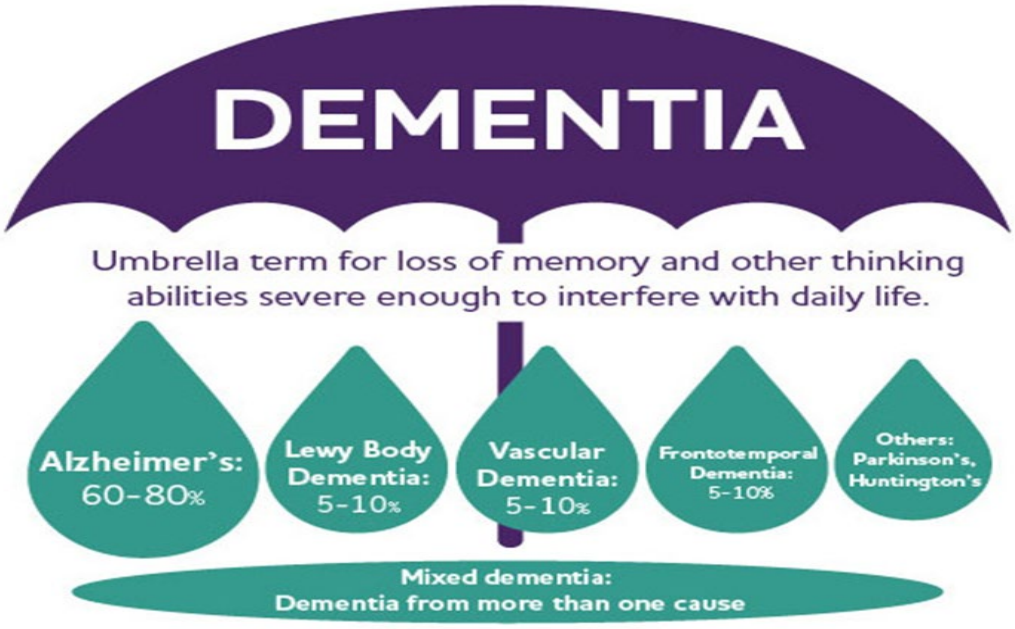
An OT practitioner's Guide to Quality Dementia Care

Speakers will use a combination of PowerPoint, case studies, and interactive learning exercises. It is beneficial if you come into the course with a basic knowledge of dementia (etiology, pathology, and progression) as well as the Cognitive Disabilities Model. Basics for each of these are provided. Also included is a list of resources and references and annotated bibliography on recent research.

What is Dementia?

- https://www.alz.org/alzheimers-dementia/what-is-alzheimers/brain_tour
- https://www.aota.org/Practice/Productive-Aging/Alzheimers-Dementia/FAQ.aspx

- Umbrella term with many types



- Not a specific disease; an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities.
- loss of mental processing that interferes with daily function
- Diagnosis based on having deficits in 2 or more areas:
    - Memory; most evident in short-term and working memory
    - Communication and language
    - Ability to focus and pay attention
    - Reasoning and judgment
    - Visual perception

Alzheimer's Disease

- Characterized by loss of function and death of nerve cells in several areas of the brain
- Plaques and tangles
- Alzheimer's Facts and Figures:
    - 6th leading cause of death in the US;
    - over 6 million Americans are living with Alzheimer's
    - 11 million Americans provide unpaid care, valued at nearly $272 billion
    - Only leading cause without a prevention, treatment or cure
    - Between 2000-2019 deaths from heart disease decreased 7.3% while deaths from ADRD have increased 145%
    - 1 of 3 seniors die with Alzheimer's Disease
    - Alzheimer's and dementia deaths have increased by 17% during the COVID-19 pandemic

In 2022, Alzheimer's and other dementias will cost the nation $321 billion

Cognitive Disabilities Model:

- https://www.crisisprevention.com/Blog/Allen-Cognitive-Disabilities-Model
- https://allencognitive.com/acls-5-lacls-5/cd-model/
- https://ottheory.com/therapy-model/allens-cognitive-disabilities-model-cdm

Important concepts:

Despite its name, the focus of the Cognitive Disabilities Model is determining a person's best *ability* to function. In dementia care, it helps us make a shift from a negative perspective about a person with dementia to a positive perspective about the person's remaining abilities. (CPI, 2023)

The Allen model helps caregivers understand the person's remaining functional ability, and caregivers can then match those abilities to tasks throughout the day that the person can still do. Through the model, we can help an individual with dementia have purpose and meaning throughout their day, rather than focusing on what they can't do or what they have lost. (CPI, 2023)
(see https://www.crisisprevention.com/Blog/Allen-Cognitive-Disabilities-Model)

The following is a description of the Allen levels:

Level 1: Automatic Actions

- Characterized by automatic motor responses and changes in the autonomic nervous system. Consciousness to the external environment is minimal.
- Automatic Actions/Reflexive--> TOTAL ASSIST
- Motor Actions: walking, eating, drinking, standing
- Attention Span: Seconds
- Activities: Sensory Stimulation

Level 2: Postural Actions

- Characterized by movement that is associated with comfort. There is some awareness of large objects in the environment, and the individual may assist the caregiver with simple tasks
- Postural Actions/Gross Body Movement-MAX ASSIST
- Motor actions: approximate imitations, pacing, bending, stretches
- Activities: gross motor games, dance
- Attention Span: minutes

Level 3: Manual Actions

- Begins with the use of the hands to manipulate objects. The individual may perform a limited number of tasks with long-term repetitive training.
- Repetitive Actions-->MOD ASSIST
- Motor Actions: manipulation of familiar objects, react spontaneously to tactile stimulation
- Attention Span: 30 minutes; no written directions; increased distractibility
- Activities: performs familiar ADL's (face washing, etc)

Level 4 Goal Directed Actions

- Characterized by carrying out simple tasks through to completion. The individual relies heavily on visual cues. He/she may be able to carry out established routines but cannot cope with unexpected events.
- Goal Directed/Familiar Activities-->MIN ASSIST
- Sensory Responds to Visual Stimuli
- Activities: Visual cues to complete tasks, matching, several step-tasks, simple crafts (2-3 steps);
- NO NEW LEARNING/GENERALIZATION
- Attention Span: Hours
- At 4.6 a person can live alone.

Level 5: Exploratory Actions

- Overt trial and error problem-solving. New learning occurs. This may be the usual level of functioning for 20% of the population.
- Independent learning/Exploratory --> self control/inclusive reasoning
- Alters actions with overt trial and error; poor organization, planning, and socialization
- Activities: Concrete tasks; NEW LEARNING AND GENERALIZATION
- Attention Span: Weeks

Level 6: Planned Actions

- Absence of disability. The person can think of hypothetical situations and do mental trial and error problem-solving. think of hypothetical situations, plan ahead to prevent mistakes
- Planned Action--> INDEPENDENT/Conceptual
- Considers consequences of actions
- Follows multi-step verbal/written cues
- ABSENCE OF COGNITIVE DISABILITY

https://passtheot.com/wp-content/uploads/2016/02/Allen-Cognitive-Levels-for-group-session-1.docx

We will be using the **Occupational Therapy Practice Framework** 4 during the case study portion of the session. You can access free with AOTA membership. Access at aota.org. Copies will be available for use.

RESOURCES

Resources for Caregivers:

- Area Agency on Aging - Aging offices are set up across the country as a resource to seniors. they provide informational resources, adult protection, ombudsman, etc.
- Home health agencies: these are designed for short term medical care in the home. They can assess nursing and therapy needs as well as assistance for bathing and other daily care. These services are covered by Medicare.
- In-home services: These are agencies that assist with personal care as well as homemaking or respite. The hours vary and can be covered either by Medicaid, veterans, long-term insurance policies, or private pay.
- Respite care: Several assisted living facilities provide day programs that keep your loved one for the day, or for a few hours to give you a respite.
- Financial services: You should consider speaking with a financial advisor or attorney regarding living wills, power of attorney, etc.
- Support Groups: Support groups in the area can help you talk about the issues that worry you. As a caregiver, you have a tough job and may need someone to talk to that understands what you are going through.

Online Resources:

https://thedevoteddaughter.com/

https://www.bonniehorsburgh.com/

Alzheimer's Association: Alz.org (general info on dementia; search site for vascular dementia)

National Institutes of Health: https://www.nia.nih.gov/health/

Mayo Clinic: https//www.mayoclinic.org>symptoms-causes>syc-20378793

Memory and Aging Center: https://memory.ucsf.edu › dementia › vascular-dementia

Dementia Care Specialists: *https://www.crisisprevention.com/Specialties/Dementia-Care-Specialists*

End of life preparation:
endoflifeguidetraining.com
protective.com/learn/how-to-build-an-in-case-of-death-binder

BOOKS:

Dancing with Elephants: Mindfulness Training For Those Living With Dementia, Chronic Illness or an Aging Brain (How to Die Smiling Book 1) by Jarem Sawatsky

Put Your Mask On First: The Caregiver's Guide to Self-Care by Dr. Gary Bradt and Scott Silknitter

Self-Care for Caregivers: A Twelve Step Approach by Pat Samples , Diane Larsen, et al.

The Art of Extreme Self-Care: Transform Your Life One Month at a Time by Cheryl Richardson

My Two Elaines by Martin J. Schreiber and Cathy Breitenbucher

Still Alice by Lisa Genova

The 36-Hour Day by Nancy L. Mace and Peter V. Rabins

Color Your Mind: A Coloring Book for Those with Alzheimer's and the People Who Love Them by Maria Shriver and Brita Lynn Thompson

Where the Light Gets In: Losing My Mother Only to Find Her Again by Kimberly Williams-Paisley and Michael J. Fox

Creating Moments of Joy Along the Alzheimer's Journey: A Guide for Families and Caregivers by Jolene Brackey

When Reasoning No Longer Works: A Practical Guide for Caregivers Dealing with Dementia and Alzheimer's Care by Angel Smits

Chicken Soup for the Soul: Living with Alzheimer's and Other Dementias: 101 Stories of Caregiving, Coping, and Compassion by Amy Newmark and Angela Timashenka Geiger

Talking to Alzheimer's: Simple Ways to Connect When You Visit with a Family Member or Friend

by Claudia Strauss

Books for children:

Something to Remember Me By by Susan V Bosak M.A

What's Happening to Grandpa? by Maria Shriver (Author), Sandra Speidel (Illustrator)

IDEAS WITH THE CAREGIVER IN MIND

- Massage
- Meal prep services
- Grocery delivery
- Medication delivery
    - Pillpack
- Community education classes offered by local universities and colleges. Topics such on health care, finances, etc may be offered.
- Yoga/other exercise classes
- Consider obtaining a Power of Attorney, general, healthcare, and/or financial
- Do you need to seek guardianship?

Resources for Dementia Practitioners:

- AOTA.org
- Claudia Allen site https://acdmweb.com/
- Dementia care specialists: Crisisprevention.com
- Allen cognitive group: https://www.allencognitive.com/
- Positive Approach to Care: teepasnow.com
- Amedeo medical literature guide (for research articles) https://amedeo.com/

Case studies:

- Mr. and Mrs. Smith
- For several years, Mr. Smith, age 63, had been having difficulties that his family found out of character. He misplaced things, would miss appointments with his plumbing clients, became lost when driving and got frustrated, and frequently lost his keys. He had always been responsible for keeping his company books. Mrs. Smith took him to the geriatric clinic after the bank talked to her son-in-law about problems with the business account.
- On medical examination, there appeared to be no other medical explanation for the symptoms. There was no evidence of hypothyroidism, vitamin B12 deficiency, or other potentially reversible causes of dementia, such as severe hypertension, stroke, kidney or heart disease. Additionally, there was no evidence of drug abuse or psychiatric illness. The physician gave the Smiths the diagnosis of probable Alzheimer's disease and referred them to the social worker and OT. Additionally, she gave them a packet of information about services available through the Alzheimer's Association.
- Social History
- The Smiths have a strong marriage. Each had their own interests and together they shared their family, church, bowling, and camping interests. They raised 3 children, 2 of whom lived within 6 blocks of their parents. Mr. Smith finished high school and completed an apprenticeship as a plumber. He worked for a company for 35 years before it closed. For the past 10 years, he managed a small plumbing company with his son-in-law. His wife is a secretary in the chemistry department at a small private college. She is 61 years old and in relatively good health. Since she began a low fat, sugar-free diet and a daily walking program, she had brought her blood sugar under control and lost 25 lb.
- The problem
- The Smiths were enjoying daily life when Mr. Smith woke up from a daily nap and was significantly disoriented and agitated. This concerned Mrs. Smith and she took Mr. Smith to the ER. It was determined that he had a UTI and was admitted for IV antibiotics. While in the acute care section of the local hospital, Mr. Smith was difficult to keep in bed, he began to scream out at the nurses as they came to do regular cares. He even went as far as to pull his catheter out stating, "it was a snake".
- OT referral
- Nursing spoke with the MD to ask for an OT consult to assess Mr. Smith and help determine his cognitive level and help them find ways to work with Mr. Smith and provide appropriate care in order for him to be able to be discharged home if that is still an option.

<u>Long term care/skilled nursing</u>:

- Quinn is an 87-year old white man with dementia. He also has a PMHx of CHF, HTN, depression, and gout. He has been living in a facility in the LTC wing for 2 years. The plan is for him to remain there for the long term.

- Dorothea is Quinn's wife. She is active with Quinn, visiting on Wednesdays and Fridays. She provides Quinn with updates on the children (2) and grandchildren's (5) activities and reads any letters that they may send. Other times, she may read the newspaper or church bulletin to help Quinn stay as mentally strong as possible. Dorothea holds Quinn's hand for the entire visit. She attends all care plan meetings and frequently speaks as an advocate on his behalf. The family lives within 2 hours of Quinn and Dorothea and visit as often as possible but due to busy lives, it ends up being about once a month.
- Quinn participates minimally. He will speak when spoken to, does not initiate conversation or activity but if wheeled to activities will passively participate. He uses simple sentences and is inconsistent with his answers. He is still able to recognize his wife but not always the children, sometimes confusing them with each other. With staff, he does not remember names but will smile when he sees someone he recognizes.
- An OT referral was initiated from nursing when the CNA noted Quinn was requiring more assistance with meals. He no longer eats in the main dining room due to facility inability to provide 1:1 assistance with meals. He has declined to dependent with self-feeding from set up only over the past 3 to 4 weeks. He has required total care for all other self-care activities since his admit and is a non-ambulator. Facility staff feel Quinn is more cognitively impaired than he appears.
- Quinn's wife expresses she would like for Quinn to retain his ability to feed himself as close to his prior level as possible and to be engaged in activities when possible so that he is not isolated and has a quality of life that he deserves. Quinn, when asked by OT, used to be quite active in his church. He attended services on a weekly basis and taught Sunday school to different men's groups. He was a high school principle for 40 years. He and Dorothea were socially active at the local county club with Quinn being part of the men's golf group and monthly card groups. Dorothea feels like she is doing all she can to engage Quinn in prior activities and interests and feels the facility could do a better job.
- Quinn has been dependent for all self-care activities with the exception of self-feeding of which was set up level only until recently. Quinn is able to perform hand to mouth with cueing and hand under hand assistance until he understands what the care giver is asking, then he is able to feed himself finger foods for about 25% of the meal.
- Quinn is distractible, but is able to respond in simple 2-3-word sentences when asked a question. If the OT asks Quinn a question about a prior interest, he is able to say more complete sentences. Quinn is able to hold 5 cards in his hand and lay them down one at a time with demonstration. He smiles when holding the cards. Quinn is also noted to perk up when church music is played nearby.

<u>Home health:</u>

- Mary is a 75-year-old lady that lives in the home with her 76-year-old husband, Ray. Mary and Ray are both retired. Mary was a homemaker and Ray was a salesman for a local distributor for animal health products. They have 5 children that are scattered around the county. The closest child is a daughter that lives 2.5 hours away. Mary and Ray live in a one level home with 3 bedrooms and 2 bathrooms, a large kitchen which opens to a family room. There is also a formal living room and laundry room. The master bedroom has a bath and it has been adapted with grab bars for the walk-in shower. Mary has a shower chair.

- Ray is always home with Mary as she needs supervision at all times. He states that he dresses, bathes and assists Mary with all her personal care. He is the primary housekeeper now and does all the cooking and shopping. He states that Mary likes to watch television while he does all the household chores. Mary is usually found to be in her recliner with the TV on, although she is not looking at the TV much. Across from Mary is a book shelf that contains many, many cookbooks and when asked, Ray states Mary loved to cook. Mary is able to ambulate without an assistive device independently. She follows directions if they are simple, one-step directions.
- OT referral
- Ray asked Mary's physician for a Home health bath aide to help with Mary's showers and personal care. The RN did the intake and felt an OT referral would benefit the case to determine Mary's level of care so that she can determine the amount of HH aide services Mary requires.

Outpatient:

- Vera is 86 and has been living at home with her husband Howard. They enjoy their large family, most of whom are local, as well as gardening and socializing with church friends. Vera is a retired nurse and has often been called upon by her family and friends for help and support.
- Vera has a history of cardiac issues including a triple by-pass surgery 2 years ago. She tries to stay active and eat healthier since her surgery. She has to take 4 medications daily, but has recently missed some doses, as noted by her husband and daughter. After noting that she was missing some things such as bill payments and medications, she was diagnosed by her primary care physician with dementia (unspecified).
- So far, she has managed with some help from her family and church friends, but recently she experienced a fall in her yard while out in the garden picking some produce. The fall resulted in aggravation of a previous back injury and has left Vera in significant pain and limits her participation in her daily activities including personal care, cooking, and leisure tasks.
- Her physician referred her to outpatient physical therapy and she has attended for 2 weeks now with some, but not expected, improvement. The lack of progress is likely due to her difficulty in completing her home exercises and management of pain medication. The physical therapist has noticed that Vera repeats her stories and does not remember that she was given home exercises or that she should be using a cane for stability. The PT worries that Vera is likely to fall again and is concerned about home safety. The PT sees the OT in the clinic and mentions his concerns.

Annotated Bibliography:

Bormans, K., & Zwakhalen, S. (2022). Using children's drawings as implicit measurements in future Alzheimer's research for the detection and alteration of negative stereotyping. *Alzheimer's Dementia.* Dec18 Suppl 9:e067593. doi: 10.1002/alz.067593.

> Children's drawings are an underused instrument in Alzheimer's research to gain insight into ways to capture young people's mental representations about old age and dementia.

Egan, K., Pinto-Bruno, A., Bighelli, I., Berg-Weger, M., van Straten, A., Albanese, El, & Pot, A. (2018). Online training and support programs designed to improve mental health and reduce burden among caregivers of people with dementia: A systematic review. *JAMDA 19* (2018) 200-206. https://doi.org/10.1016.jamda.2017.10.023.

Evidence of improvement using internet-based intervention was studied, including mental health outcomes for caregivers. However, further research is indicated.

Gonzalez, J., Mayordomo, T., Torres, M., Sales, A., & Melendez, J. (2015) Reminiscence and dementia: a therapeutic intervention. *International Psycogeriatrics* 27:10, 1731-1737.

This study provides support for the effectiveness of integrative reminiscence therapy as an intervention in people with dementia, especially for reducing depressive symptoms and improving psychological well-being.

Harmer, B., & Orrell, M. (2008). What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging and Mental Health.* vol. 12, No 5.

People with dementia, staff, and carers had differing views about what made activities meaningful. Organizational limitations and social beliefs limited the provision of meaningful activities for the population. The study also indicates areas for improving activities in care homes.

Harrison, K., Garrett, S., Halim, M., Sideman, A., Alison, T., Dohan, D., Naasan, G., Miller, B., Smith, A., & Ritchie, C. (2022). "I didn't sign up for this": Perspectives from persons living with dementia and care partners on challenges, supports, and opportunities to add geriatric neuropalliative care to dementia speciality care. *Journal of Alzheimer's Disease* 2022;90(3):1301-1320. doi: 10/3233/JAS-2205-220536.

Findings highlight enormous gaps in supports and systems available for caregivers and those with ADRD. Current supports are insufficient to navigate extensive challenges of the disease process.

Huang, H., Kuo, L., Chen, Y., Liang, J., Huang, H., Chiu, Y., Chen, S., Sun, Y., Hsu, W., & Shyu, Y. (2013). A home-based training program improves caregivers' skills and dementia patients' aggressive behaviors: A randomized controlled trial. *American Journal of Geriatric Psychiatry* 21:11.

Researchers tested theory-based caregiver training program and found improvements in caregiver's preparedness, competence and self-efficacy and decreased aggressive behaviors.

Jiang, F., Cheng, C., Huang, J., Chen, Q., & Le, W. (2022). Mild behavioral impairment: an early sign and predictor of Alzhiemer's disease dementia. *Current Alzheimer's Res.* doi:10.2174/1567205019666220851145 28.

This article addresses early detection of AD, looking for link between mild behavioral impairment (MBI) and early AD. Results indicate MBI may be an early detector of AD and the early intervention for MBI may have a positive effect on alleviating long-term cognitive decline.

Joshi, M. & Galvin, J. (2022). Cognitive resilience in brain health and dementia research. *Journal of Alzheimer's Disease* 2022;90(2):461-473. doi: 10.3233/JADS-220755

Researchers define and explore shift in research focus from dementia risk to addressing disease resistance and resilience including identification of genetic variants. They additionally summarize recent studies demonstrating the study of resilience in caregivers that may have direct and indirect impact on quality of care and patient outcomes.

McCurin, N., McCarthy, L., Arsenault, L., Showalter, E., & Patterson, B. (2022). Dementia care coordination: Evaluating a program to support caregivers through collaboration with the Alzheimer's association and health care partners. *Alzheimer's Dementia* 18 Suppl9:e059900. doi: 10.1002/alz.05990.

Dementia Care coordination is a successful program to meet the needs of and improve outcomes for caregivers. Support, education and resources are pivotal in managing the stresses of the disease process.

McLaren, A., LaMantia, M., & Callahan, C. (2013) Systemic review of non-pharmacologic interventions to delay functional decline in community-dwelling patients with dementia. *Aging Mental Health, 17(6):* 655-666. doi:10:1080/13607863.2013.781121.

This is a systematic literature review studying caregiver burden contribution to long-term placement. The goal was to determine if non-pharmacological intervention could delay decline in those with dementia. The literature provides evidence that these interventions can delay progression of functional impairment or disability.

Reuben, D., Panlilio, M., & UCLA Alzheimer's and Dementia Care Program (2022). Effects of an Alzheimer's and dementia care co-management program on quality, clinical outcomes, and utilization. *Alzheimer's Dementia* Dec;19 Suppl 9:e63939. doi: 10.1002/alz.063939.

This article studied a program providing support and education. The program can improve quality and clinical outcomes and reduce health care utilization and costs. It suggests the program can be implemented across diverse health systems.

Schussler, S., Zuschnegg, J., Paletta, L., Russegger, S., Fellner, M., Ploder, K., Strobi, B., Sekulic, M., Koini, M., Hofmacher-Holzhacker, M., & Roller-Wirnsberger, R. (2022). Experiences of people with Alzheimer's disease relatives, and dementia trainers on the usability of a tablet-based dementia training. *Alzheimer's Dementia.* Dec18 Suppl 2:e062097. doi: 10.1002/alz.062097.

Results show that the presented tablet-based dementia training is received well by participants, but there is still potential for technical enhancements regarding support through the exercises and motivational strategies.

Rosende-Roca, M., Canabate, P., Moreno, M., Preckler, S., Seguer, S., Esteban, E., Tartari, J., Vargas, L., Narvaiza, L., Pytel, V., Bojoryn, J., Alarcon, E., Gonzalez-Perez, A., Gurruchaga, M., Tarraga, L., Ruiz, A., Marquie, M., Boada, M., & Valero, S. (2022). Sex, Neuropsychiatric profiles, and caregiver burden in Alzheimer's disease dementia: A latent class analysis. *Journal of Alzheimer's Disease* Aug 9. doi: 10.3233/JAD-215648.

Caregiver burden is highly dependent on the patient's behavior symptoms. Female caregivers provide care to patients that pose a greater burden, which makes them more susceptible to become overwhelmed.

Smit, D., deLange, J., Willemse, B., Twisk, J., & Pot, A. (2016). Activity involvement and quality of life of people at different stages of dementia in long term care facilities. *Aging & Mental Health.* vol 20, No. 1, 100-109. doi: 10.1080/13607863.

This study aims to provide insight into the value of activity involvement for quality of life of long-term dementia care residents, taking resident characteristics and cognitive status into account. Activity involvement is an important contributor to higher well-being in long-term care.