



**Advancing Dementia Care: Insights  
into New Care Approaches for Home  
Care and Beyond**

CEU Event

[comforcare.com](https://comforcare.com)



# Key Learning Objectives

- Define dementia and highlight why caregiving for individuals with dementia differs from other types of caregiving.
- Describe the key stages of disease progression and the importance of recognizing how these stages impact caregiving strategies and decisions.
- Identify and discuss care strategies that are grounded in evidence-based practice, highlighting the effectiveness of advanced staff training.
- Describe three best practices for aligning care strategies with the individualized caregiver plan of care — ensuring that care is person-centered and effective.

A photograph of a caregiver in blue scrubs sitting and talking to an elderly woman with white hair and glasses. The caregiver is on the left, and the elderly woman is on the right. They are in a well-lit room with a window in the background. A small potted plant is visible on a table to the right. The text is overlaid on the image.

Define dementia and why caregiving differs from other types of care.

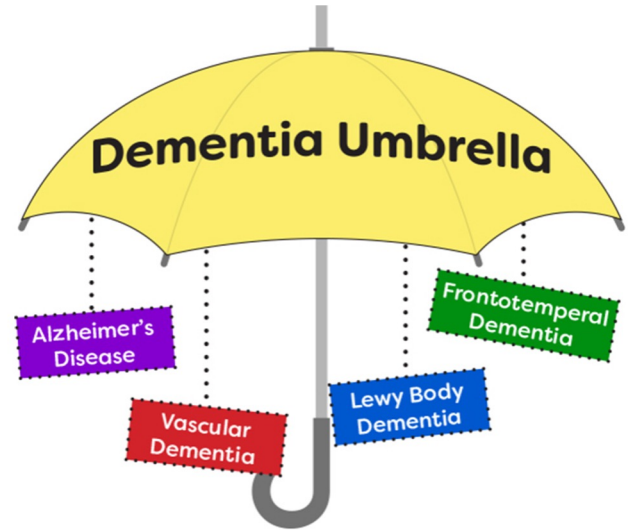
# Dementia

**Definition:** An observable, irreversible decline in enough to affect the person's daily life including:

- Memory and attention
- Orientation to time, place or person
- Processing information
- Language, reasoning and judgement
- Regulating emotions

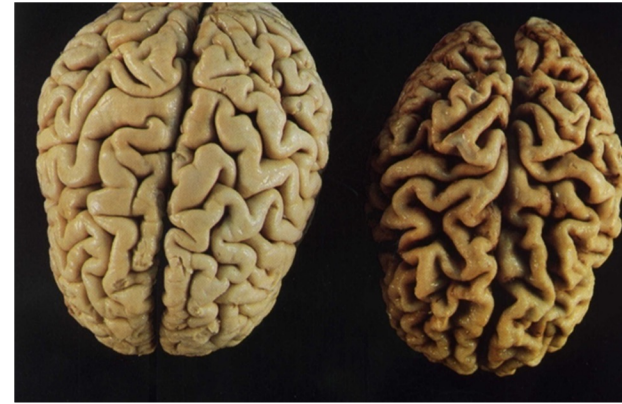
**Dementia is an umbrella term;** there are many types of dementia.

- Alzheimer's disease is the most common type of dementia
- **Cause:** It depends on the type. Many have unknown causes. A history of stroke, head injury or family history can increase risk.



# Dementia

- Currently, no cures or disease-modifying treatments.
- Reducing symptoms with medicines and pharmacological interventions improve quality of life.
- Early detection is challenging because the onset is gradual, mistakes are subtle and symptoms can be inconsistent and go unrecognized.
- Neurons in the short-term memory center are among the first affected.
- Symptoms progress along a continuum from forgetfulness to a need for total assistance with self care, incontinence and a failure to recognize relatives, including spouses.
- Progression is marked by problems with language, apraxia, agnosia and challenging behaviors.



# Care Requires a Different Approach

- The person with dementia is experiencing their environment differently.
- 14 functional areas impacted.
- Care and support needs to be sensitive to the person as an individual.
- As caregivers we must take an approach to observe and help interpret what the person may feel or what reactions mean.
- Care requires a person-centered care approach.

As the disease progresses, behavior, needs, abilities and understanding all begin to change requiring the caregiver to be an expert noticer and teamplayer adjusting our approach to the needs of the individual.

# Person-Centered Care

## It is a philosophy of care

- It calls us to get to know individuals and their situations through an interpersonal relationship.
- Achieving PCC requires *everyone* play a role in delivering person-centered care.
- A personalized approach optimizes quality of life and is the best way to help people live happier, healthier lives at home—or in a place that feels like home—as long as possible.



# Person-Centered Care

## Where did it come from and what does it mean?

- Tom Kitwood (1980s) - British psychologist
- Defined dementia care as: “Treating just the disease, or thinking of the dementia diagnosis alone, is the wrong approach—due to a highly variable, progressive condition without a cure.”
- Challenges us to be *aware* of symptoms while looking deeper to see what’s beneath behaviors.
- Dementia is best understood as an interplay between neurological changes and psychosocial factors. These **factors may hold clues for why the person feels or behaves the way they do– if the person can’t fully tell us.**
- Requires us to recognize dementia is constantly impacting the person’s brain.
- Emphasizes careful observation, positive communication, and authentic relationships.



# Person-Centered Care


## Five fundamental principles:

1. **Maintain personhood**; it's what makes you *you*.
2. **Foster relationships with respect, trust, and recognition**. Strive to know the person beyond the diagnosis, physical or cognitive limitations.
3. **Support social engagement**. Person-centered care helps people create and maintain a sense of community with others through engagement in meaningful social activities.
4. **Create comfortable, flexible, safe environments** that enable the person to do what they want and need to do and are in tune with the person's evolving needs.
5. **Adjust care and strategies as the person and/or their situation changes. We accept the challenge to change with individuals, adapting our support based on preferences, histories, and current needs and abilities as their life is still unfolding.**

# Person-Centered Care

## Benefits

- Optimizing **quality of life, maintaining dignity, showing respect,** and **allowing an individual to retain lifetime values** lead to greater acceptance of care and more meaningful, positive moments.
- Practical benefits include:
  - reduced agitation and aggression
  - reduced need for particular medications
  - reduced depression
  - optimized cognitive function
  - improved overall quality of life for the person with dementia and their caregivers!



**There's a lot we can improve about how we help support individuals despite having no cure yet for the disease itself.**

# Functional Abilities

## Areas Lost

1. Gait and balance
2. Movement body mechanics
3. Executive function
4. Immune function
5. Swallowing
6. Language
7. Orientation
8. Fine and gross motor coordination
9. Planning, starting and completing tasks, and sequencing of tasks
10. Situational memory
11. Communication
12. Continence
13. Short-term Memory
14. Sensory processing

## Areas Preserved

1. Emotions
2. Personal Preferences
3. The Need to be in control
4. Social chit-chat
5. Senses
6. Social contact
7. Cognitive and intellectual stimulation
8. Long term memory
9. Life with meaning and purpose
10. The need to be and feel safe
11. The need to communicate
12. Capacity for and the need to feel pleasure
13. Music and Rhythm
14. Motor Memory

# Activity

## Write out your:

1. Favorite activity for exercise
2. Favorite holiday meal
3. Favorite meal you still enjoy cooking
4. Topic you feel you're most knowledgeable about and enjoy sharing that knowledge with others
5. Choice you made today on what you wore for work - pants, skirt, shorts, leggings, etc.?
6. Favorite person you speak with over the phone
7. Favorite person you love having an ongoing chat conversation with
8. Next vacation you can't wait to go on
9. Favorite game you like to play
10. Favorite memory from this past weekend

## Write out your:

1. Food item you cannot stand eating
2. Preference - coke or pepsi?
3. Favorite way to enjoy creative freedom - reading a book or magazine, seeing a play or symphony?
4. Favorite band or song from your early 20s
5. Time you like to eat breakfast on most days. Or, not at all.
6. Preferred dinner - heavy meal or lite?
7. Favorite thing about spring time
8. Favorite scent
9. Favorite ways to get exercise
10. #1 person or way that makes you feel safe (i.e., spouse, door lock, alarm, etc.)



Changing your  
perspective, changes  
your experience..

# Recap

- Person-centered care (PCC) is a philosophy of care built around the needs of the individual. It calls us to get to know individuals and their situation through an interpersonal relationship.
- Five fundamental principles of PCC philosophy are 1) Maintain personhood, 2) Foster relationships with respect, trust, and recognition, 3) Support social engagement, 4) Create comfortable, flexible, safe environments, and 5) Adjust care plans and strategies as the person and/or their situation changes.
- For people living with dementia, a whole dynamic situation is constantly impacting the person's brain function, behavioral responses, functional abilities, and sense of well-being—not just their dementia.
- The good news is there is lots we can notice and improve about the situation and how we help our clients, despite having no cure yet for the disease it

A young woman with long dark hair, wearing teal scrubs, is sitting on a white sofa. She is pointing at a tablet computer held by an older woman with short blonde hair and glasses, wearing a white blouse. The older woman is smiling and looking at the tablet. A white cup of tea on a saucer is on the sofa next to them. The background is a bright, airy room with white pillows.

Describe the key stages of disease progression in dementia and impact on care.

# Timeline of Dementia

- Dementia's timeline is explained in three levels:
  - Early
  - Middle
  - Late
- Note: it can be helpful to divide the middle stage into a first and second half to better understand some of the toughest challenges.
- Staging helps determine how much help and what kind of help individuals may need.

Nearly 7 million Americans are living with Alzheimer's disease (AD). By 2050, this number is projected to rise to nearly 13 million. AD was the fifth-leading cause of death among people age 65 and older in 2021.



# Early Stage

The Alzheimer's Association points to difficulties that, if the problems were new or unusual for the person, could signal an early sign of brain change and should be checked out by the doctor. Some of those signs include:

- Coming up with the right word or name
- Remembering names when introduced to new people
- Having difficulty performing tasks in social or work settings
- Forgetting material that was just read
- Losing or misplacing a valuable object
- Experiencing increased trouble with planning or organizing
- If a familiar routine is interrupted, they might have to start all over again from the beginning
- Difficulty adapting to a new situation
- Difficulty problem solving
- Slow or delayed reaction in a potentially unsafe situation

# Early Stage - Challenges

In the early stage of this disease, when short term memory is lacking, people rely on situational memory and can make more mistakes if the routine changes. Some additional challenges include:

- Keeping appointments
- Recalling familiar places or people
- Managing money
- Keeping track of medications
- Organizing daily routines
- Navigating or driving to unfamiliar places
- Recalling proper words or names
- Locating household items
- Occasional atypical behavior
- You may also notice a person struggle with a familiar activity when something in the environment is missing, steps are out of order

# Early Stage - Impact on Care

- Support and assist with the routine, making it as predictable as possible.
- Consider making a written reminder of the daily routine, like a “cheat sheet.”
- Caregivers, we gotta be ready to flex, because people in early-stage dementia just aren’t as flexible as they once were.
- They still want and need to be engaged in meaningful activities.
- The emotional tone of your communication is important because people in early-stage dementia don’t want to feel incompetent (honestly, does anyone?).
- Look around the environment. Are there things in the environment that support the routine?
- Always build in opportunities for the person to make choices and offer simple choices.

# Middle Stage First-Half Signs

- The routine isn't enough anymore
- Situational memory is not as strong
- Executive function mishaps start significantly impacting functional status and safety
- Executive function involves several aspects of memory and thinking including:
  - planning events and actions
  - focusing and directing thoughts
  - organizing, making calculations, making decisions, paying attention
  - using self-control
  - demonstrating flexibility and problem solving
  - imagining potential outcomes

# Middle Stage First-Half Challenges

- Wearing the same clothes
- Sleep patterns change
- Organizing food and drinks can lead to individuals skipping meals or over-eat the wrong things, forget to drink healthy fluids
- May start struggling with bowel and bladder routines
- Communication is also changing, but those mistakes may be subtle.
- Immediate recall is starting to change which is the memory file for what just happened—it's that fast, what you just said

# Middle Stage

## First-Half - Impact on Care

- Motor memory and emotional memory is still viable
- Using the right communication approach is key
- Communication must shift from facts—with long explanations and instructions—to a focus on the feelings
- Expect repeated questions
- Engaging in meaningful activities can be a proactive strategy for dealing with distress

# Middle Stage Second-Half Signs

- Step-by-step setup isn't enough anymore
- Motor memory becomes compromised
- Individuals needs hands-on care, but they resist touch and assistance because it feels uncomfortable, startling, or intrusive. This results in distress in the form of resistance to care
- Less coordination and doesn't use objects as well, touching everything as they are exploring through their senses
- This can be a difficult time since some of the challenges in this stage don't have a "quick fix"

# Middle Stage Second-Half - Challenges

- Motor memory declines
- Walking changes become more obvious
- Language and formal language is now deteriorating
- They may require several additional seconds to process, understand and respond
- Immediate recall continues to deteriorate and repetitive comments or questions may come back-to-back-to back
- Individuals may be asking to go home
- More sensitivity to the environment when things used to be fine now feel uncomfortable
- Constant supervision and flexible hands-on assistance is needed around the clock



# Middle Stage

## Second-Half - Impact on Care

- Use the right communication approach
- Incorporate social chit-chat, provide slow, simple instructions, and plenty of visual cues
- With personal care get on the person's level, position yourself beside them, not in front or overhead: to the side
- Address signs of distress and focus away from the facts and focus on the feelings
- Limit napping or incorporate a short nap earlier in the day. Stay active during the day, aiming for 30 minutes of aerobic exercise per day
- Increase light exposure which has healthy chemical effects in our brain and body

# Late Stage

In the late stage, individuals require around-the-clock assistance with daily personal care

Just like in earlier stages, changes in your client's behavior and functional status can be road signs that they've progressed to the late stage of the disease.

# End Stage Signs

- The person may seem like they're stuck on go or on stop
- The person in the late stage needs physical help getting started, even moving out of a chair or taking the first step in standing
- Fall asleep and sleep for days
- As motor memory and situational awareness continue to fade
- Losing awareness of recent experiences and their surroundings
- Their communication is severely limited—you'll hear sounds more than words
- People in late-stage dementia still want and need friendly connection. They may not respond with words, but if you watch closely and give them more time to respond, they may reward you with a smile, wink, or hum

# End Stage - Impact on Care

- If you notice this person enjoying an activity, it may look like they're just watching or imitating others, but that could be the just-right-participation for them
- They also need us to place things in their visual field, or they can't see them
- In addition to worsening vision, your client may also exhibit some new reflexes at this stage as sensory processing and motor control continue to decline. A tale-tell sign is that automatic grasp reflex
- During personal care, music, and other rhythmic language like chit-chat and prayer can all ease the person's distress
- Clients with late-stage dementia will eventually have difficulty swallowing, and aspiration pneumonia is predictable when the brain loses control over the automatic movements inside the body
- Your clients in this late stage are vulnerable to infections as the disease progresses due to the breakdown of the immune system
- Everyone on the home care team must be ready at any time to implement the person's advanced directives

## Pop Quiz! First Half of Middle Stage

**Q: What is a good example of what not to do when someone is experiencing distress in first half of middle stage:**

- a. If your communication strategies for dealing with distress are falling flat at first, remember to check yourself and stay calm.
- b. Ask to put a schedule together of the day's activities and point out what still needs to be completed.
- c. Enter the person's reality.
- d. Listen, affirm the person's feelings, and redirect. Spend more time empathizing with feelings before changing the subject or asking the person to do something.
- e. Consider putting the person on the team by inviting them to help you with a productive activity.

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- e. Consider putting the person on the team by inviting them to help you with a productive activity.

## Pop Quiz! Second Half of Middle Stage

**Q: What are some of the key areas that are deteriorating in the second half of middle stage dementia? Choose all that apply.**

- a. Simple-self care tasks
- b. Fluctuation in specific times of the day where clients will need more help
- c. Not sure what to do with common objects
- d. Proprioception declines - increased fall risk
- e. Communication
- f. Immediate recall
- g. Situational memory
- h. More sensitive to the environment
- i. Executive function
- j. Sensory processing
- k. Incontinence

## Pop Quiz! Second Half of Middle Stage


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# Recap

- Every person's experience of dementia is individual, but we can predict some common challenges in each stage and become expert noticers and creative problem solvers as our clients' needs and abilities change.
- Dementia's timeline is often explained in three levels (early, middle, and late), but it can be helpful to divide the middle stage into a first and second half to better understand some of the toughest challenges.
- Tailor interventions based on the client's unique needs, personal preferences, and *preserved strengths*, not just losses
- Changes in memory, language, judgement, impulse control, sensory processing and motor coordination appear like road signs
- Caregivers need to know the road signs to notice the progression and typical fluctuations



Learn evidence-based practice strategies, highlighting the effectiveness of advanced staff training.

# What do teams need?

- Opportunities to:
  - Recognize and describe challenges
  - Assess root causes to get to the heart of the matter in real cases
  - Create case-specific plans and implement with teamwork
  - Return to their team for ongoing problem solving
  - Result when done well is it improves care coordination and service delivery
- Knowledge translation - how do we take our knowledge and apply to effectively support those living with dementia?

## D.I.C.E. (**D**escribe, **I**nvestigate, **C**reate, **E**valuate) four-step process for **team problem solving**

- Important because dementia-related challenges rarely have quick fixes. Experienced caregivers say, **“When it comes to dementia, it’s not just what you do, but how you do it.”**
- Research suggests that a standardized process for problem solving is equally as important as a dementia-specific knowledge and skills
  - DICE guides the team through a coordinated process of figuring out when and how to apply those proven interventions in practice **(Application)**
- Teams need to collaborate to solve the real-world problems **(Knowledge Translation)**

The best evidence among non-drug approaches is for those that focus on training caregivers—whether they are spouses, adult children or staff in nursing homes and assisted living facilities—to make behavioral and environmental interventions.

The researchers, from the University of Michigan Medical School and Johns Hopkins University, reviewed two decades’ worth of research to reach their conclusions about drugs like antipsychotics and antidepressants, and non-drug approaches that help caregivers address behavioral issues in dementia patients.

They lay out their findings along with a framework that doctors and caregivers can use to make the most of what’s already known. Called DICE for Describe, Investigate, Evaluate, and Create, the framework tailors approaches to each person with dementia, and as symptoms change.

# Culture Change

- [www.pioneernetwork.net](http://www.pioneernetwork.net)

Inspiring culture change, supporting innovation, providing an opportunity for learning. Pioneer Network is the national leader of the culture change movement, helping care providers to transition away from a medical, institutional model of elder care to one that is life affirming, satisfying, humane and meaningful. Pioneer Network advocates for a culture of aging in which individual voices are heard and individual choices are respected. Our goal is transformational culture change in organizations to foster care that is directed by the person receiving it.



**Vox**  
by **Design**

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# Recap

- Consider DICE and Culture change as effective advanced training approaches.
- Continue to find ways to implement purpose into daily life of others.



Discuss best practices for aligning care strategies with the individualized caregiver plan of care.



# Best Practice Considerations

- Get to know the individuals you're caring for.
- Consider a team-centered approach to care.
- Understand your clients place in the timeline of dementia and match the approach to best support it, and always be ready to flex.

# Resources

- [Alzheimer's disease 2024 Facts and Figures](#) (Alzheimer's Association)
- [Alzheimer's Foundation of America](#)
- [Dementia Action Alliance](#)
- [DementiaWise®](#) (ComForCare Home Care / At Your Side Home Care)
- [NIA-Funded Imbedded Pragmatic AD/ADRD Clinical Trials \(IMPACT\) Collaboratory](#) (National Institute on Aging)
- [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act and the 2022 National Strategy to Support Family Caregivers](#) (Administration for Community Living)
- <https://www.pioneernetwork.net/>
- <https://diceapproach.com/>



Thank you!



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