

**A Foundation for Person-centered
Care Practices**



DEMENTIA **Live**TM

*“Because it’s frightening to care for
someone you don’t understand”*

Ann Catlin, OTR, LMT

AGE·u·cate[®]
Training Institute

Summary

As the population of people living with dementia rapidly expands, care providers must learn new ways to understand, and respond to, the needs of these individuals.

Dementia Live™ provides an “inside-out” understanding of dementia and serves as the foundation upon which other person-centered practices can be built.

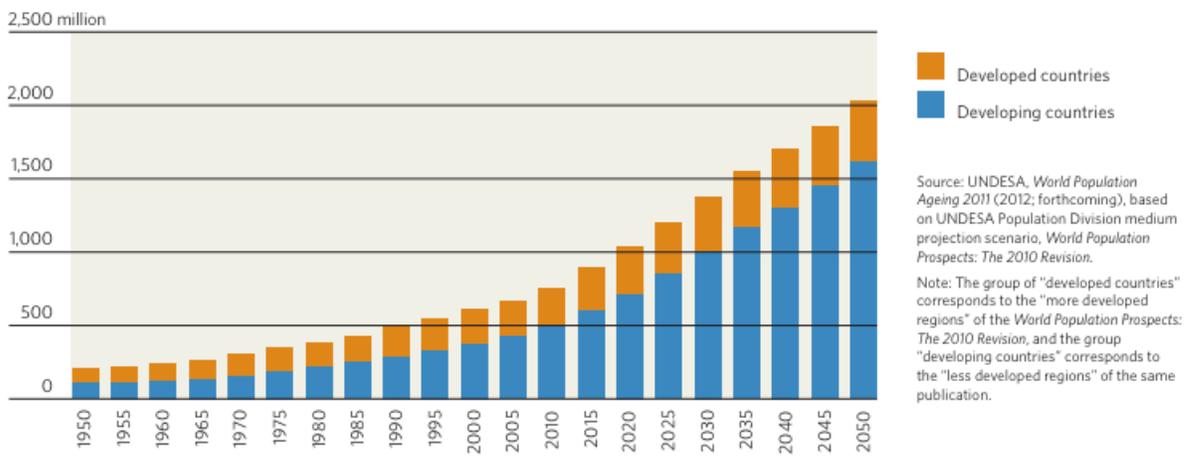
This paper offers an overview of Dementia Live™ and its rationale resulting from a combination of published research and literature as well as clinical and personal experience of the professionals who developed the program.

The Need: An Aging Population and the Dementia Explosion Worldwide

It's no secret that the world population is aging. Because dementia impacts every health and social care system in the world, we have turned to the World Health Organization and Alzheimer's Disease International to report on current facts and future trends and needs. ^{1, 2}

- By 2050 the world population over age 60 will be 2 billion.

Number of people aged 60 or over:
World, developed and developing countries, 1950-2050



The total number of new cases of dementia each year worldwide is nearly 7.7 million, implying one new case every four seconds.

World Health Organization

- The prevalence of dementia doubles every five years after age 65.
- Although dementia mainly affects older people, it is not a normal part of aging.
- The total number of people with dementia worldwide in 2010 is estimated at 35.6 million and is projected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.
- Dementia is a major cause of disability in older adults and the leading cause of need for care.
- The estimated cost of dementia worldwide in 2010 was 604 billion US dollars.

- Life expectancies of people with dementia average 4-7 years after diagnosis.
- The impact of living with dementia is extreme for the person with the condition, their families and other care partners.
- No cures or treatments to significantly alter the course of the disease are currently available.

The report concludes that initiatives supporting and improving the lives of people with dementia, their families and other care partners should, in part:

- Promote a dementia-friendly global society.
- Improve public and professional attitudes and understanding of dementia.
- Invest in health and social systems to improve care and services.
- Optimize physical health, cognition, activity and well-being.

Changing the Paradigm: Person-Centered Care

Person-centered care is a moral philosophy of care that honors individual history, personality and preferences in one's daily routine. The focus is on the person rather than on the illness or disability and the person's voice is heard in decisions about how to best provide care.

Dementia initiative.
Dementia Care: The Quality Chasm ³¹

There is a movement to reframe dementia care from a biomedical to person-centered models.

Traditionally the biomedical model has been applied to dementia, emphasizing progressive neuropathology and its effects on brain cellular changes, disability and loss of function. Care based on this model focuses on physical safety, medication and other interventions to manage symptoms.

Today, initiatives around the world are not only changing how care practices are carried out, but how people living with dementia are characterized by the organizations and individuals who care for them.

Definitions of person-centered care vary somewhat, but many relate to Kitwood's ⁵ groundbreaking work in the 1990s with emphasis on personhood.

The British National Institute for Health and Clinical Excellence describe the elements of person-centered care as: ⁴

1. The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them.
2. The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia.
3. The importance of the perspective of the person with dementia. Looking at the world from the perspective of the person with dementia and recognizing that each person's experience has its own psychological validity and that people with dementia act from this perspective and that empathy from this perspective has its own therapeutic potential.
4. The importance of relationships and that people with dementia need an enriched social environment that both compensates for their impairment and fosters opportunities for well-being.

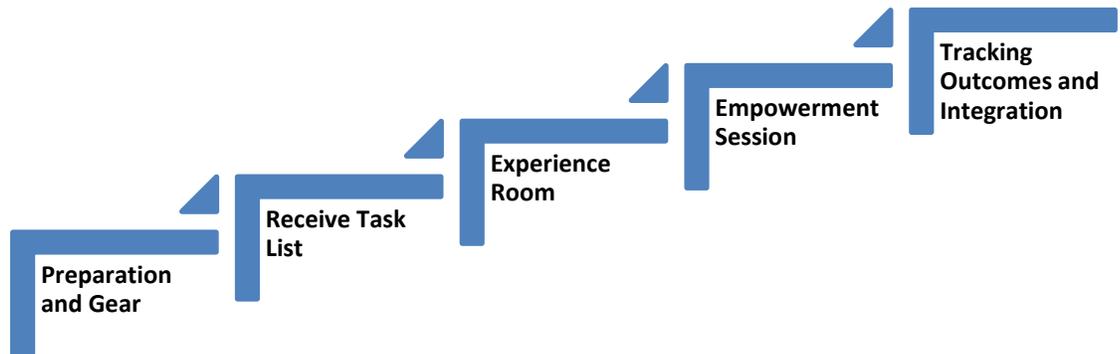
This framework informs care providers, policies, leadership, skill development of staff, care protocols, and engagement with individuals and families utilizing services, gradually shifting the culture of care of people with dementia.

Answering the Need: Dementia Live™

To elevate person-centered care practices, care providers must first gain an understanding of what dementia is and how the individual with dementia feels when challenged with cognitive and sensory changes.

Dementia Live™ is experiential learning that simulates cognitive and sensory impairment, giving participants a real-life simulation of what it must be like to live with dementia. Participants gain greater awareness and understanding of the constant struggles affecting persons with dementia as they go about their daily lives. Greater understanding leads to more sensitive care partnering.

The Dementia Live™ Method and Rationale



Preparation and Simulation Gear.

Participants are outfitted in the gear needed to produce the dementia simulation experience. The gear is designed to simulate common age- and dementia-related vision, auditory and tactile sensory changes. Such gear consists of headphones and an MP3 player loaded with specially selected background noise, overlaid with random startling sounds and voices; eyewear with modified lenses restricting light and peripheral vision; gloves to alter peripheral tactile sensation and motor skills.

What follows is a summary of sensory changes that informed the development of the simulation gear.

Sensory Changes Associated with Aging and Dementia

The ability to take in and respond to what we see, hear, touch, smell, and taste changes with age even without the effects of dementia. Environmental and health factors play a role as to when these changes begin and their rate of change. For example, prolonged loud noise affects hearing, smoking affects taste and smell sensitivity, and health conditions such as diabetes and macular degeneration affect vision. One's ability to process sensory data is further compromised when compounded by the effects of dementia.

Vision.

Vision is a complicated process involving interpretation of meaning from the visual information gained through eyesight.

Although many age-related vision changes are considered normal, they can cause problems by interfering with activities of daily living.

Age-related vision changes result in: ^{19, 20}

- Increased lighting requirements
- Decreased ability to adjust to bright light and/or darkness
- Reduced contrast sensitivity
- Decreased ability to judge depth perception
- Decreased ability to focus close up
- Increased sensitivity to glare
- Decreased color sensitivity

Dementia-related vision changes:

Vision sense changes greatly during the course of dementia. Neurological changes in the brain result in further visual impairment, leading to confusion about what the person is experiencing in his surroundings.¹⁴

- Field of vision becomes increasingly narrow
- Glare interferes with accurate perception of objects and the environment
- Increased problems with depth perception
- Contrast sensitivity dysfunction, resulting in difficulty identifying objects set against a background consisting of similar colors
- Many have difficulty recognizing common objects (visual agnosia)
- Visual hallucinations

Hearing.

Hearing sounds and understanding those sounds are two different abilities.

Age-related changes in hearing, known as presbycusis, result in decreased ability to: ^{19, 32}

- Detect high and/ or low frequency sound
- Discriminate or identify words
- Distinguish foreground from background sounds, making it difficult to hear in noisy environments

Dementia adds to auditory processing impairment, resulting in these further changes: ^{14, 15, 18}

- Decreased ability to interpret sounds and words accurately
- Slower processing time
- Words and sounds coming across as garbled, distorted and meaningless
- Difficulty sorting out noises, resulting in excess noise confusion, overstimulation and agitation

Tactile:

Age-related changes in tactile/somatosensory processing include: ^{17, 19}

- Decreased light touch sensitivity
- Impaired peripheral sensation
- Increased thresholds for pain and temperature
- Decreased position and movement sense

Scherder (2011) concludes, “the effect of age on touch (somatosensory system) is noteworthy since a decrease in the processing of tactile stimuli by the upper extremities, particularly the hands and fingers, and the mouth has serious consequences for ADL (activities of daily living) and food intake respectively. This sequence of events negatively influences the level of physical activity. An age effect has also been observed for static and dynamic position sense, reducing postural stability and, again, physical activity.”

Dementia-related tactile changes:

- Primary tactile function may not be affected drastically beyond age-related changes, with the exception of

decreased stereognosis [the ability to recognize objects through touch].¹⁸

In summary, changes in vision, hearing, and tactile processing especially affect persons with dementia since they are the primary senses by which information is taken in and analyzed by the brain, informing one's ability to respond and function. These and other sensory changes are a result of the disease process and must be accounted for in the delivery of care of people living with dementia, including Alzheimer's disease.

Receive Task List

Task List

Once the gear is in place, each participant is directed to perform a list of activities that will take place in the Experience Room. Directions are given verbally with minimal visual or tactile cues. The standardized tasks have been selected based on functional activities one might perform in a typical day—for example, locating and hanging clothing or counting coins.

Experience Room

Experience Room

Participants perform assigned tasks in a space set up to replicate the environment in which individuals with dementia may reside, such as a studio apartment with distinct kitchen, living, and bedroom areas. All items needed to perform the tasks are strategically placed prior to participants entering the room. The space has been tailored with attention given to privacy, lighting, furnishings, ease of navigation, and safety.

The Experience Room leader conducts systematic observation, using a standardized protocol, of each participant's approach to the tasks along with reactionary behaviors. Behavioral expressions triggered in the dementia simulation are representative of well-documented behaviors of people with dementia when they are faced with tasks or environments that they experience as challenging or overwhelming. It's important to acknowledge that behavioral expression is highly individualized, stemming from each person's personality, life experience, stress resilience, and neuropathology of the disease resulting in dementia.

Such behaviors include, but are not limited to:^{3, 26, 27, 28, 29, 30}

Physical Expressions:

- Withdraws, sits down, stands in corner
- Resists activity

- Attempts to leave
- Shadows or follows others
- Gathers or clings to objects
- Rummages or searches
- Wanders aimlessly
- Repeats actions

Vocal Expressions:

- Asks for help
- Repeats vocalizations
- Swears
- Talks to self

Emotional Expressions:

- Gives up, “shuts down”
- Becomes angry
- Makes self-deprecating comments
- Laughs
- Cries



Empowerment

During the Empowerment Session participants examine their experience of and reaction to the dementia simulation, reflecting on their feelings, thoughts, and behaviors. Comparisons are made to how people living with dementia may feel, think, and act in the presence of diminished sensory and cognitive function. Care partners are empowered with tangible and emotional understanding of influences on the behavior of individuals in their care. This understanding becomes the foundation for improving relationships, communication and care practices.



Tracking Outcomes and Integration

Tracking the impact of Dementia Live is important in order to influence integration of improved care practices in a sustainable way. Observable outcomes of Dementia Live highlight staff experience and satisfaction of work life; elder/resident/patient

experience of and participation in daily life; family engagement; and business/ organization impact.

Attitudes, Stress, and Satisfaction of Staff Who Care for Residents with Dementia

Sheryl Zimmerman and Colleagues. The Gerontologist (2005) ²¹

Purpose of Study: Considering the increasing proportion of residents in long-term care who have dementia, and the important influence that direct care providers have on resident quality of life, this study explores the dementia-related attitudes of residential care/assisted living (RC/AL) and nursing home staff, as well as their work stress and satisfaction.

Design and Methods: Data were derived from interviews with 154 direct care providers from 31 RC/AL facilities and 10 nursing homes who participated in the Collaborative Studies of Long-Term Care.

Results: Stress was more often reported by care providers who had been working for 1 to 2 years (compared with longer); in addition, those who had been working for 1 to 2 years were more likely to espouse hopeful or person-centered attitudes than those who had been working for a longer period of time.

Also, a person-centered attitude related to satisfaction, and perceived competence in providing dementia care was consistently associated with dementia-sensitive attitudes and job satisfaction.

Implications: Attending to the welfare and ongoing training of workers who have demonstrated job commitment may lessen their tendency to become jaded over time or seek job opportunities elsewhere.

Further, the attitudes the staff hold related to dementia and the training they receive to provide dementia care are important for their own well-being.

The Power of Experiential Learning

*Tell me and I forget.
Teach me and I
remember. Involve me
and I learn.*

Xun Kuang

The developers of Dementia Live believe that in order for a learning process to change knowledge, attitudes or action in care practices, the learner must be engaged on a cognitive and emotional level. Kolb's experiential learning model²³ and an earlier model called confluent education²⁴ have guided the program's development. Experiential learning has been defined as "learning in which the learner is directly in touch with the realities being studied" in a way that bridges the gap between cognitive and affective learning.^{22, 23}

Kolb's process represents a cycle where the learner experiences, reflects, thinks, and acts. Concrete experiences lead to observations and reflections about the experience. These reflections are then absorbed and processed into concepts which lead to motivated action.

Confluent education is described as four domains:

1. *Readiness.* Willingness and preparation for learning.
2. *Cognitive/Mind.* Information and intellectual process.
3. *Affective/Feelings.* Emotional reaction during and after the learning activity.
4. *Responsibility/Application.* Harnessing the relevance of what is learned and making a connection to everyday life or work.

Kolb's Experiential Learning Cycle and Confluence Learning Domains and Dementia Live™

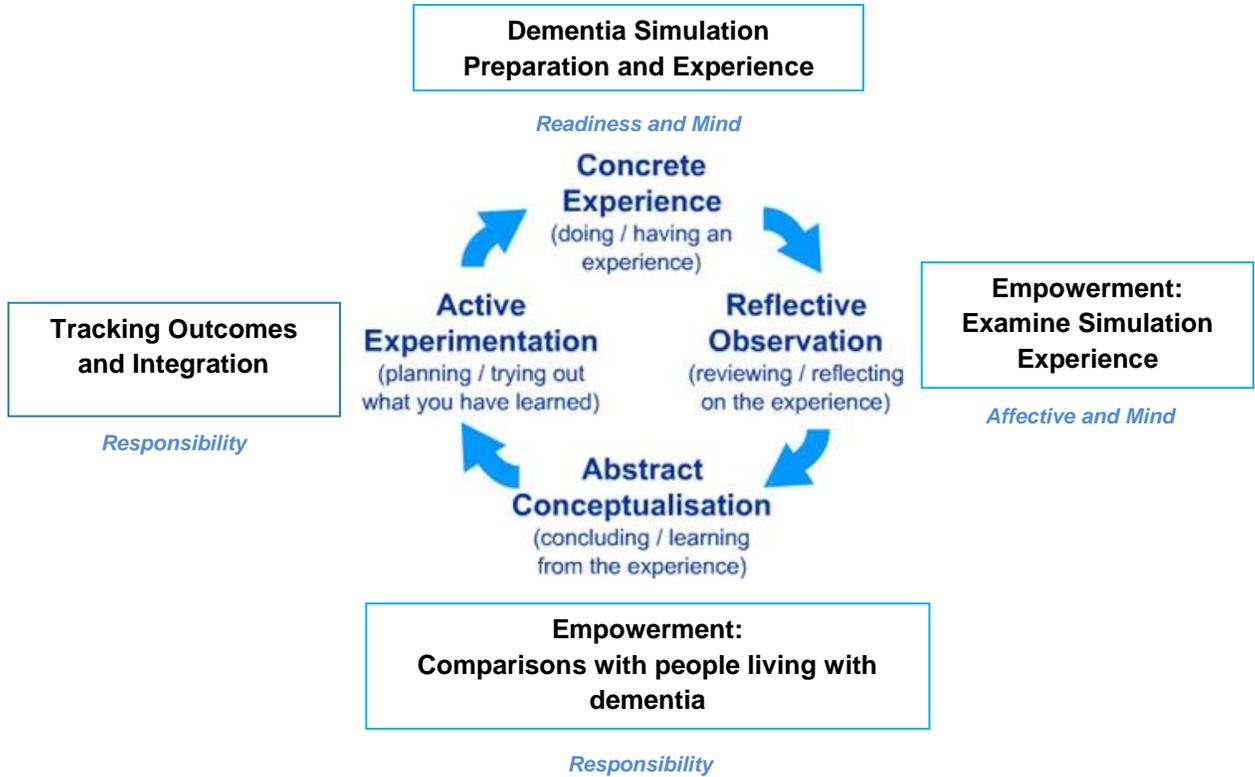


Image Source: ²⁵

Developing a Skilled and Empathic Workforce

The elements and impact of Dementia Live reflect the Dementia Core Skills Education and Training Framework established by Skills for Health and Health Education England, including dementia awareness, basic skills and leadership in integrating person-centered practices.

Education, training and skills acquisition are a hallmark of good dementia care.

Alistair Burns, National Clinical Director for Dementia, NHS England

Regardless of the setting—private residences, community senior services, assisted living and skilled nursing, and acute hospitals--there are growing concerns that the current eldercare workforce is not prepared to manage the exponential growth of dementia.

Professional and family care-partners, along with other staff members such as housekeeping, maintenance, dietary, transport drivers, beauticians, barbers, and office workers all interact with people with dementia, and therefore need to have an understanding of dementia and develop skills in how to relate to and support those affected. A reasonable question may follow: What skills do they need?

In an effort to answer this question, a collaborative project emerged from the Skills for Health and Health Education England in partnership with Skills for Care. They developed the Dementia Core Skills Education and Training Framework, which outlines the essential skills and knowledge necessary for anyone working in settings accessed by people with dementia.

They describe these three tiers: ⁶

Tier 1: **Dementia awareness.** Knowledge, skills and attitudes for *all* those working in health and care settings.

Tier 2: **Basic Skills:** Knowledge, skills and attitudes needed for roles that have regular contact with people living with dementia.

Tier 3: **Leadership:** Enhancing the knowledge, skills and attitudes for key staff (experts) working with people living with dementia designed to support them to play leadership roles.

Essential components of each tier include, but are not limited to: ⁶

1. Dementia Awareness:

- Dementia and associated symptoms
- Importance of recognizing a person with dementia as a unique individual
- The experience of living with dementia

- Reasons why a person with dementia may exhibit signs of distress and how behaviors seen in people with dementia may be a means for communicating unmet needs

2. Basic skills:

- Communicating effectively and compassionately with individuals who have dementia
- Promoting health, well-being and independence
- Caring for those at the end of life
- Managing the role of pharmacological intervention

3. Leadership:

- Person-centered dementia care processes
- Families and care team as partners in dementia care
- Evidence based practices
- How to lead in transforming dementia care

Empathy

At the core of person-centered dementia care is relationships. Therefore, the role of empathy must be considered. Empathy has long been identified as a desired quality in health care professionals, linking it to improved patient and care provider satisfaction scores.

According to Waal⁷, “empathy is the capacity to be affected by and share the emotional state of another, assess the reasons for the other's state, and identify with the other, adopting his or her perspective. Simply put, “empathy is being able to put yourself in someone else’s shoes for a while so you can imagine what it is they are going through.”⁹

There are two distinct types of empathy. *Affective empathy* refers to feelings that arise in response to another person’s emotion or experience. *Cognitive empathy* refers to the ability to recognize and understand another’s emotions and reactions to their experiences.⁸

Dementia Live helps develop empathy, a personal quality and a professional skill that inspires care partners to feel, think and act in ways that promote a better environment in which to live, work and visit.

Conclusion

“The incredible, complex journey of caregiving begins with understanding.”

Pam Brandon, President
Age-u-cate Training
Institute

By temporarily and safely immersing participants in the life of dementia, we begin to change their existing attitudes about dementia, which opens the door to deepening their understanding of dementia and improving their actions of care. Learning, language, and cultural barriers are minimized because everyone who experiences Dementia Live is going to *feel* the difference.

Dementia Live provides a tangible, real-life experience for family members, healthcare professionals, coworkers and friends who are at a loss when it comes to understanding the complexities of the disease. It teaches them how to respond to the cognitive, emotional and behavioral changes presented by individuals with dementia.

When people are engaged intellectually, emotionally, socially, soulfully, and/or physically, we can begin the journey of true person-centered care.

That is the power of Dementia Live.



We seek to create transformative change for an aging world.

We achieve this by delivering high impact solutions to usher in a new culture of service for those who live in, work and visit your community or organization.

For a Free Consultation:

(817) 857-1157

www.ageucate.com

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