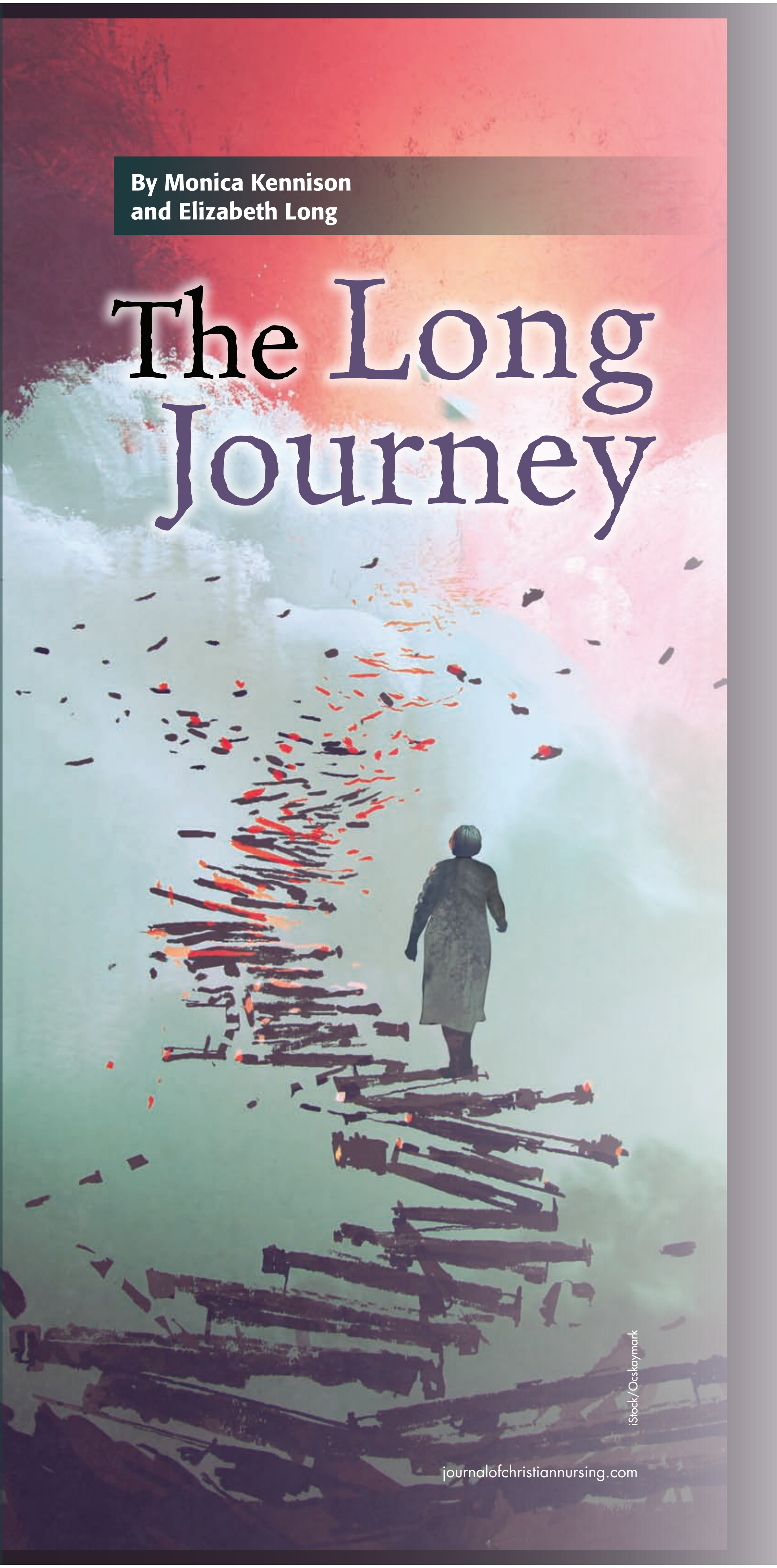
CE 2.0 contact hours

The Long Journey

By Monica Kennison and Elizabeth Long



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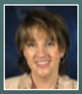
ABSTRACT: The growing elderly population is creating record numbers of individuals with Alzheimer's disease (AD) and other dementias. Nursing has an unprecedented opportunity to rethink how we care for adults with dementia, reduce the burden of caregivers, and preserve the personhood of patients. This article reviews AD and dementia pathophysiology, history, screening, stigma, treatments and interventions, and caregiver support. A nurse's journey with her mother with AD imparts the meaning of patient dignity.

KEYWORDS: aging, Alzheimer's disease, caregivers, dementia, Music & Therapy™



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The manuscript by Dr. Long was accepted by peer-review 11/6/2017; the manuscript by Dr. Kennison was accepted by peer-review 2/18/2018.

The authors declare no conflict of interest.

DOI:10.1097/CNJ.0000000000000529

# of Alzheimer's Disease

The world population is aging dramatically—the number of people over age 60 is expected to double between 2000 and 2050 (World Health Organization [WHO], 2014). Globally, a drastic increase in those with Alzheimer's disease (AD) and other forms of dementia is anticipated. Alzheimer's is the most common type of dementia in persons over age 65, accounting for 60% to 70% of all cases. Worldwide, 50 million people have dementia, the seventh leading cause of death (WHO, 2017, 2018).

The number of older adults in the United States also is growing substantially. In 2014, there were 46.2 million adults over the age of 65, accounting for 14.5% of the population; by 2015, the number rose to 47.8 million adults over 65. In 2030, it is predicted there will be more adults over the age of 65 than persons 18 years and younger. In 2060, the projected population of adults 65 and over is 98.2 million (United States Census Bureau, 2016, 2017).

Currently, 5.7 million persons are diagnosed with dementia disorders, with predictions that by 2050 the number could increase to 16 million (Alzheimer's Association, 2018a). Poised at the forefront of elder care, nursing has an unprecedented, albeit daunting, opportunity to rethink how we care for those with dementia, reducing the burden of caregivers and preserving the personhood of patients.

HISTORY & PATHOPHYSIOLOGY

In 1906, Alois Alzheimer, a German psychiatrist and neuroanatomist, reported a "peculiar severe disease process of the cerebral cortex" in a 50-year-old female, who presented with paranoia, progressive sleep and memory disturbances, aggression, and confusion (Hippius & Neundörfer, 2003, p. 1).

Alzheimer discovered the distinctive changes in the brain responsible for the irreversible destruction of neurons, particularly those in the cerebrum and hippocampus. The actual neurodegeneration that causes progressive alterations in memory, learning, and mood begins more than a decade before the clinical diagnosis (Jack et al., 2013). Although complete pathophysiology is not fully understood, amyloid plaques and neurofibrillary tangles are classic pathological signs of AD, beginning in the medial temporal lobes, then the parietal lobes and lateral frontal cortex. These amyloid plaques have been found to primarily consist of *beta-amyloid*, a protein fragment. The neurofibrillary tangles consist of the protein *tau*. The tau protein is thought to undergo abnormal phosphorylation in the development of these tangles. Free radicals, produced by oxidative stress, also are considered part of the pathology and contribute to cellular damage (Alzheimer's Association, 2018b).

AD is an age-related, multifactorial disorder with genomic components. The greatest risk factor is increasing age. *Late-onset* AD (after age 65) accounts for 90% of cases and typically manifests in the mid-60s, with memory loss that disrupts daily living (National Institute on Aging [NIA], 2016). A variation of the Apolipoprotein E gene has been linked to increased susceptibility to late-onset AD (NIA, 2015). Three genetic mutations are said to have a causative link to *early-onset* (prior to age 65) or *familial* AD, although the link explains less than 5% of cases worldwide (Schutte, Davies, & Goris, 2013) (Table 1).

Alzheimer's is a progressive disorder. In early stages, participation in meaningful conversation and activities may be impaired. Possible issues are repeating stories or having difficulty finding the right words. In the middle stage, communication issues worsen, resulting in speaking

Table 1. Risk Factors for Alzheimer's Disease

Increasing age (highest risk factor): prevalence rates of 5% after age 65 that rise to 30% after age 85.
Gender: incidence is similar between males and females; prevalence is higher in females due to longer lifespan.
Race/ethnicity: higher prevalence in African-American and Hispanic populations.
Health risks: cardiovascular disease, diabetes mellitus, obesity, smoking, chronic inflammation (assorted causes), prior head injury.
Educational: associated with lower educational level.
Genetics: high-level genetic testing can be performed, but newer self-ordered tests using saliva may reveal genetic risks.
• **Autosomal dominant inherited AD** is associated with up to 3 genetic mutations and with early-onset AD.
• **Apolipoprotein E (APOE) genes** (APOE 2, 3, and 4) are *susceptibility (nondeterministic) genes;* polymorphism occurs on chromosome 19.
• **APOE 4 variant** is associated with increased risk for late-onset AD; 50%–70% of those with AD have at least one APOE 4 allele. Those with two copies of APOE 4 have higher risk for late-onset AD. This does not imply carriers will get AD (NIA, 2015).

less often, reverting to a native language, or relying on gestures more than speaking. In late stages, an individual may rely on nonverbal communication, including facial expressions or vocal sounds (Alzheimer's Association, 2018c). (Sidebar.)

STIGMA

Behavioral and psychological symptoms of dementia (BPSD) describe untoward behaviors that may occur with AD and other dementias. These include aggression, agitation, depression, mood changes, and other inappropriate behaviors. Agitation, one of the predominant behaviors in BPSD, can result in increased social isolation, which promotes further communication decline and decreased quality of life (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; Kales, Gitlin, & Lyketsos, 2014).

The stigma of AD is pervasive, as noted by Kuriakose (2012):

> Some mistakenly perceive AD as a normal part of aging, a mental illness, or something metaphysical related to the supernatural or spiritual beliefs. People with dementia are often isolated, or hidden, because of stigma or the possibility of negative reactions from neighbors and relatives to behavioural and psychological symptoms. The idea that nothing can be done to help people with dementia often leads to hopelessness and frustration. (p. 2)

An AD patient gives a poignant example: "It's almost as if they are afraid of bringing up the subject. Being a cancer survivor, I was constantly asked how I was doing, while I was going through treatment. With Alzheimer's, no one asks" (Batsch & Mittelman, 2012, p. 8). Stigma may be worse in those with limited disease knowledge, limited contact with persons with AD, and when AD occurs in men or younger persons (Herrmann et al., 2017).

Persons living with AD are being recruited to stigma-reducing projects, such as communities like the Dutch village of Hogeway, where all residents have dementia (Planos, 2014), and the Alzheimer's Association (2018d) Early-Stage Advisory Group. Those living with AD proffer a unique perspective and are essential assets to stigma reduction, advocacy, and policy change.

TREATMENT & INTERVENTION

The U.S. Food and Drug Administration has approved multiple medications to treat global function, behavioral symptoms, and declining cognition in people with AD and other dementias (NIA, 2018) (Table 2). For common behavior changes in the mid to late stages of AD, nonpharmacological interventions are preferred, although medication may be necessary to help the person regain control and be less disruptive (Fletcher, 2012, p. 170). Antipsychotics are not recommended for use in patients with dementia. There is a black box warning due to increased mortality with their use (Food and Drug Administration, 2013). The American Psychiatric Association recommends use only when there is an imminent threat to the patient or others, and at the lowest dose possible for the shortest amount of time (Yohanna & Cifu, 2017). When caring for persons with AD, be vigilant about assessing side effects, while teaching safe medication administration and the hazards of drug interactions, especially with over-the-counter medications, dietary supplements, and herbs (Zwicker & Fulmer, 2012).

In concert with medications, nonpharmacological interventions for AD include cognitive training (CT), physical activity, and psychosocial, behavioral, and environmental interventions such as communication, implementation of person-centered care, redirection, and finding the underlying cause of a behavior. Promising results of CT were found in the Advanced Cognitive Training for Independent and Vital Elderly study in healthy adults over a 10-year period (Rebok et al., 2014). Computerized speed-of-processing CT yielded a statistically significant impact on cognitive decline. Nurses can explain that CT appears to have cognitive benefits for healthy adults, although there is no conclusive evidence that CT prevents AD (Bahar-Fuchs, Clare, & Woods, 2013).

Physical exercise is a promising intervention that may improve ability to perform activities of daily living (ADLs) in persons with dementia (Forbes, Forbes, Blake, Thiessen, & Forbes, 2015). Although the most effective type, amount, and duration of exercise has yet to be determined, ample evidence exists to incorporate regular exercise as an intervention for those with mild cognitive impairment and AD.

Nurses can individualize behavioral, psychosocial, and environmental interventions to address the most troubling symptoms of AD—agitation, aggression, and wandering (Fletcher, 2012). For instance, maximizing safe function may involve teaching the caregiver to limit choices, reduce stimuli with agitation, and anticipate physical stressors, such as hunger or thirst.

Researchers are seeking to identify biomarkers for AD in the preclinical stage so that early intervention can begin (Maruszak & Thuret, 2014). In 2017, the National Academies of Sciences, Engineering and Medicine committee of experts concluded that the evidence is encouraging but inconclusive to support three interventions that may be effective to stave off the progression of cognitive decline: CT, managing hypertension, and physical activity (aerobic exercise, strength training) (Downey, Stroud, Landis, & Leshner, 2017).

CAREGIVER COPING

Nurses can help caregivers with showing unconditional positive regard for the person with AD, regardless of troublesome behavior (Fletcher, 2012). Nurses are instrumental in incorporating interventions for family caregivers of persons with AD who express religiosity, or an openness to learning how religiosity may impact caregiving. They can help address difficult questions such as, if one loses cognitive awareness, do you lose your ability to conceive of God (McGee & Myers, 2014, p 62)? Church attendance (Sun & Hodge, 2014), group spiritual therapy (Mahdavi, Fallahi-Khoshknab, Mohammadi, Hosseini, & Haghi, 2017), and spiritual care education (Salamizadeh, Mirzaei, &

Table 2. Medications Used in Treatment of Alzheimer's Disease (AD) and Other Dementias

CLASS	ACTION	MEDICATIONS	SIDE EFFECTS
Cholinesterase Inhibitors (first line of treatment)	Prevent acetylcholine breakdown (for neurotransmission); lose effectiveness over time as disease progresses	*Donepezil (Aricept)* for mild, moderate, severe AD	Nausea Vomiting Diarrhea Dyspepsia Weight loss Muscle cramps Muscle weakness Fatigue Give with food to decrease gastrointestinal side effects.
	Prevent acetylcholine and butyrylcholine breakdown	*Rivastigmine (Exelon)* for mild to moderate AD	
	Increase acetylcholine; stimulate nicotinic receptors to produce more acetylcholine	*Galantamine (Razadyne)* for mild to moderate AD	
N-Methyl-D-Aspartate Receptor Antagonists	Appear to decrease symptoms of AD overall, possibly by decreasing the neurotransmitter glutamate, which can cause brain cell death in excessive concentrations	*Memantine (Namenda)* for moderate to severe AD *Namzaric*, a combination of Namenda/Aricept for severe AD	Diarrhea, constipation, dizziness, confusion, headache, weight loss/gain Give without regard to food intake.
Symptom Management:			
Selective Serotonin Reuptake Inhibitors	Help relieve depression by inhibiting serotonin reuptake	*Citalopram (Celexa)*	Dizziness Fatigue Headache Somnolence Insomnia Constipation Diarrhea Dry mouth Nausea Vomiting Dyspepsia Give without regard to food intake.
Selective Norepinephrine and Serotonin Reuptake Inhibitors	Help relieve depression, generalized anxiety disorder, fibromyalgia, chronic musculoskeletal pain	*Duloxetine (Cymbalta)*	
Antidepressants	Weakly inhibit norepinephrine, dopamine, and serotonin reuptake Tricyclic antidepressant	*Bupropion (Wellbutrin)* *Mirtazapine (Remeron)*	
Use with Extreme Caution:			
Hypnotics	Sleep aid	Example: *Zolpidem (Ambien)*	Amnesia Mood swings Headache Drowsiness Depression Dizziness Lethargy Confusion Fall risk Anorexia Weight gain/loss Diarrhea/constipation Dyspepsia Nausea/vomiting
Anticonvulsants	Used to manage severe aggression, seizures, depression	*Sodium valproate (Depakote)*	
Antianxiety Agents	Decrease anxiety	*Lorazepam (Ativan)*	
Antipsychotics	Treat hallucinations, paranoia, agitation, aggression, irritability when symptoms are severe, dangerous, or cause significant distress to the patient. Use lowest effective dose for least amount of time.	*Quetiapine (Seroquel)* *Risperidone (Risperdal)*	

Source: NIA (2018)

Ravari, 2017) have been linked to positive outcomes in familial AD caregivers. Among female caregivers, religious involvement was linked to "better adaptation independent of age, race, education, caregiver health, care recipients' health, social support, and health behaviors" (Koenig, Nelson, Shaw, Saxena, & Cohen, 2016 p 582). Data from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II study linked positive religious coping with positive aspects of caregiving and social support (Heo & Koeske, 2013).

The most successful interventions for family care providers are multidisciplinary, use a variety of tailored components, incorporate active involvement (such as homework), and maintain ongoing contact with the *care dyad*—the caregiver and the person with AD (Wennberg, Dye, Streetman-Loy, & Pham, 2015). The REACH II and REACH VA clinical trials used a 6-month social/behavioral intervention to improve caregiver coping skills and care recipient management. Data yielded significantly decreased burden, depressive symptoms, caregiving frustrations, and troubling dementia-related behaviors, compared with control groups (Nichols et al., 2017). Use of humor also is a significant predictor of Alzheimer's caregiving competence (Llanque et al., 2015).

Existing outcome measures of familial AD caregivers focus primarily on the negative, such as burden and depression (Stansfeld et al., 2017). However, dyadic psychosocial interventions yield positive outcomes for caregivers. Not surprisingly, factors such as gender and culture, as well as the care recipients' behavioral and mental health symptoms, impact outcomes (Wennberg et al., 2015). Self-efficacy, spirituality, resilience, rewards, gain, and meaning are associated with positive aspects of caregiving (Stansfeld et al.).

Practical tips for caregivers include speaking slowly and distinctively in a calm manner, approaching the person from the front, calling him or her by name, saying who you are, and keeping good eye contact. Use positive, friendly, nonverbal communication. Remember those with dementia need extra processing time so wait patiently for a response or wait, then speak again. Repeat information and questions, if needed. Provide solutions, rather than asking questions. For example, say, "Your dinner is here on the table," instead of asking, "Are you ready for dinner?" Visual cues are helpful, such as pointing to or touching an item (chair, hairbrush, etc.) you want the person to use, or start a task to prompt him/her to begin an activity (Alzheimer's Association, 2018e).

Keeping written track of valuables, especially between moves to domiciliary or long-term care facilities, and making sure family members know who has which items can reduce stress. When assisted living becomes needed, consider selecting a facility that provides different levels of care, including hospice, without moving the loved one to another facility.

Healthcare professionals influence the quality of life for individuals with dementia. As the disease progresses, appropriate social and physical environments are key. Using multimodal evidence-based interventions, nurses can lead efforts to improve the care of those with AD and their caretakers to achieve the best-possible outcomes. A tone of promise and hope must never falter in nurses' shared journey with people with AD, as we focus on whatever is true, noble, right, pure, lovely, and admirable (Philippians 4:8, NIV).

Web Resources

- Alzheimer's Association—https://www.alz.org/
- Alzheimer's Association Caregivers Center—https://www.alz.org/care/
- Alzheimer's Disease International—https://www.alz.co.uk/
- Alzheimer's Foundation of America—https://alzfdn.org/
- AARP Caregiver Guides—https://www.aarp.org/caregiving/care-guides/
- Cognitive Assessment Tools—https://www.alz.org/professionals/healthcare-professionals/clinical-resources/cognitive-assessment-tools
- Folstein Mini-Mental Status Exam—https://tinyurl.com/y7hym9cf
- National Institute on Aging—https://tinyurl.com/ya3kqo9n
- Music & Memory™—https://musicandmemory.org

A Mother-Daughter JOURNEY Through Alzheimer's

By Monica Kennison

Mom and I slowly turned the street corner, heading up the hill to my home. I marveled at Mom's effortless walking, knowing the progressive cognitive decline of Alzheimer's disease, already assaulting her independent living, would eventually consume her body.

Suddenly, Mom turned her head, and asked, "Won't your mother worry that you're out after dark?"

Time stood still, as our footsteps stopped. We stared at one another. I focused on her face, hoping for the slightest recognition. *Will she know me? Am I prepared for the answer?*

"You're my mother," I announced with an ear-to-ear grin.

Surprise and a huge smile lit her face. "Jiminy crickets! I'm your mother?" Still smiling and pointing to herself, she said, "Me? I'm your mother?" with her voice rising at the end, as though trying to convince herself.

"Yes, you're my mother," I confirmed. My wide smile never faded as the pure joy of her response tugged at my heartstrings.

I and my two sisters often wondered if Mom still recognized us, yet suspected the knowing left long ago. A year earlier, one sister confessed, "I think Mom just thinks I'm a nice lady who takes her shopping and to lunch." We never wanted to ask the hard question, for fear of the truth that Mom had, indeed, forgotten who we were. I suppose the revelation that evening should have saddened me, but I felt elated at her spontaneous reaction. It was one of those special moments when I willed time to stand still. If the imprisoned apostle Paul could spread the good news to his jailer (Acts 16:16-40), then I could not only accept, but appreciate, this time with Mom and her unrelenting disease. Surely, I could embrace our evolving relationship, nurture God's spirit within us, and learn to be content whatever the circumstances (Philippians 4:11).

As a nurse, I knew the staggering numbers of persons with AD. As a daughter, I focused on just one. I understood the negative physical and mental outcomes that family caregivers tend to experience. However, I vowed to view the positive aspects of Mom's AD and not dwell on feelings of sadness and loss. "I can do all things through Christ who strengthens me" (Philippians 4:13, NKJV) allowed me to develop the self-efficacy associated with positive aspects of caregiving (Salamizadeh et al., 2017). Mom's wish was not to become a burden to her children; we vowed to embrace the lessons she proffered while raising us, dismissing any notion of being defined by the disease that afflicted her.

After we returned home from that walk, and Mom was tucked in bed, I thought of when she was first diagnosed. Mom had been found confused and wandering at dusk on the four-lane highway a mile from her home. Thankfully, the police picked her up, unharmed. Our older brother, Mom's first emergency contact, met the police at her home. He took Mom to the Emergency Room for evaluation. That visit, while confirming no physical ailment, started a cascade of diagnostic tests and follow-up services, one of which was with a psychiatrist.

"Rose," the psychiatrist deadpanned, "Why do you think all your daughters have come with you today?" He skipped over the small talk.

Cheerily, Mom smiled and offered, "Well, I don't know. I guess because they're concerned about me."

With no attempt at conversation, he segued into a series of questions, his stone-face belying friendly bedside manner.

"Who is the president of the United States?"

"Kennedy, isn't it?" Mom offered in an unsteady voice, signaling her uncertainty.

"No, Mom, that was several presidents ago," I mused.

"What year were you born?" he continued.

"1943," she announced confidently.

Whew, s*he got that right.*

"What is your address?"

A pregnant pause followed. "Sidney Street. I live on Sidney Street," Confident, yes; accurate, no. I heaved a heavy sigh.

What day is it?

I silently begged, *please remember.* As she struggled to find the answers, tears welled in my eyes. How degrading this line of questioning was for my mother and best friend. The anticipatory grief we had been staving off for months, fueled by our denial, was becoming, before our eyes, real and painful and sad.

As a nurse, I knew the psychiatrist was doing his job, although I wished he had been more relational. As a daughter, I wanted to preserve Mom's dignity. My precious mother was reduced to a cruel diagnosis. I somehow was overcome by a feeling of vulnerability for Mom. Like most family members with a loved one diagnosed with AD, the normal reaction of grief began that fateful day and continued unabated throughout the disease progression (Arruda & Paun, 2017). No longer would Mom be the lively consummate Grammy. No longer would she be preparing the holiday meal. No longer would she stay with our kids, while my husband and I vacationed.

Tears dropped silently onto my lap, as the physician droned on about the changes we could expect and how he was concerned about Mom's safety, living alone. After grabbing a prescription for Namenda® and making a follow-up appointment, we dashed out of the office and headed to Mom's house, supposedly to plan how we could keep Mom in her home longer.

After parsing available community resources, my siblings and I created a schedule of Monday-Wednesday-Friday home healthcare aides for bathing and grooming, Meals-on-Wheels for lunches, daily evening visits during the week by our older brother, and weekend overnight stays at my sister's house or mine. Another sister who lived in Denver agreed to provide telephone reassurance on Tuesdays and Thursdays. Mom's care was manageable. That is, until I pushed the limits.

I was too slow in accepting that Mom could no longer safely drive. One day when she commented that she wished she could still drive, I ignored my brother's admonition that Mom was incapable of driving, handed her the keys, and settled into the passenger seat for what I hoped would be validation. Mom's distractibility and indecisiveness led her into oncoming traffic, sudden jerky stops, and near-miss collisions, before I insisted she pull over. Despite my foolishness, God kept us safe, as he promises (Psalm 116:6, NIV). After that incident, we sold Mom's car.

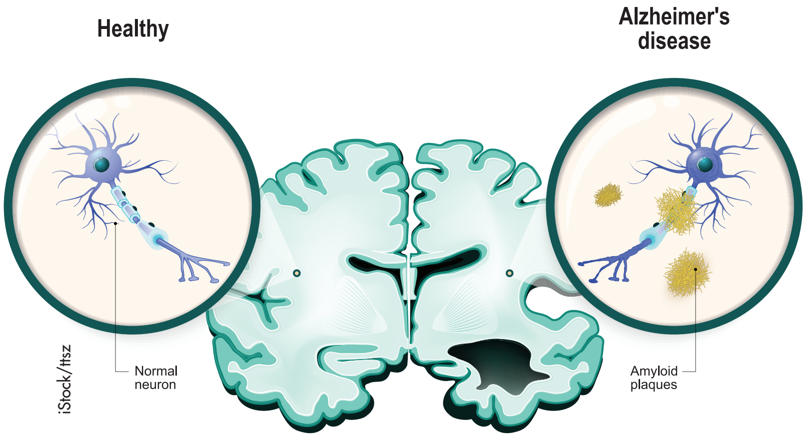
Mom's cognitive decline was not all sad and gloomy. When she visited, she took our youngest son's room. One morning she walked out wearing boys' white underwear, *over* a pair of athletic shorts, topped with a tie-dyed t-shirt. Baseball socks and high-top sneakers completed the ensemble. After I stifled a giggle, I decided it might be time to lay out Mom's clothes.

For the next several years, our structured plan allowed Mom to live at home, until she was found wandering in the neighborhood again. Mom transitioned to a domiciliary home for a year, then when her caretaker fell ill, we placed her in long-term care. When Mom vacillated between lucidity and confusion, she often remarked, "I don't want to be a burden. Put me in a home when it comes to that." When Mom died, a sister and I were at her bedside, singing the classic hymn, *Mansion over the Hilltop*, reading stories in *Guideposts* magazine, and reciting her favorite Bible passage, Psalm 23.

Some of Mom's most enduring lessons led me to become a better nurse. In life, she was my best friend, so it seemed fitting to use the Best Friends Approach to person-center her care (Bell & Troxel, 2012). In so doing, I found ways to honor her life story.

It has been many years since my mother passed away; however, I still feel the loss and reflect on sweet memories of the woman who guided me through life and instilled the desire and confidence to conduct myself in a manner that would bring honor and glory to God. Her unselfishness, meekness, and love of God are traits I attempt to pass on to my own family and bring to my care as a nurse.

UNDERSTANDING ALZHEIMER'S DISEASE AND OTHER DEMENTIAS



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Alzheimer's Disease (AD), the most prevalent dementia, can begin in the 30s but is a disease of aging; 10% of all individuals over age 70 show evidence of significant memory loss; more than half of this group has AD. Initial symptoms may be insidious, and onset begins years before symptom awareness. Duration is 8 to 10 years before death, with a range of 1 to 25 years. Lesser amounts of pathology probably occur in non-AD patients, but to a greater extent in AD (Seeley & Miller, 2016).

- *Early stage* involves memory impairment, often considered as benign aging forgetfulness, followed by progressive language and visual spatial deficits. Memory loss is noticeable in the *mild cognitive impairment* phase. As symptoms progress, word-finding, navigation, and organizational difficulties occur. Over time, cognitive deficits interfere with daily life.
- *Middle stage* creates need for daily supervision. Confusion and apraxia develop, with difficulty managing sequential motor tasks, naming, comprehension, and language fluency. Visual spatial deficits cause problems with activities of daily living, inability to read clocks, or do calculations.
- *Late stage* commonly involves aimless wandering; a shuffling gait may emerge. Delusions can occur, especially focused on theft and infidelity. Judgment and reasoning become lost; disinhibition, belligerence, and arguing develop. Eventually, person becomes rigid, with muteness and incontinence. Death comes from secondary infections, coronary artery disease, pulmonary emboli, malnutrition, or aspiration (Seeley & Miller, 2016).

Vascular Dementia (poststroke, multi-infarct dementia) is about 10% of all dementias. Impaired judgment, difficulty organizing, making decisions, and planning help distinguish vascular dementia from AD, where memory impairment is the primary presenting symptom (Alzheimer's Association, 2018f).

Dementia with Lewy Bodies involves aggregations of alpha-synuclein protein in the cortex, called *Lewy bodies* (same as in Parkinson's disease patients, but in a different pattern). Presents with memory loss and thinking disorders, with symptoms of visual hallucinations, sleep disturbances, gait imbalance, and parkinsonian movements (Alzheimer's Association, 2018g).

Parkinson's Disease Dementia is caused by alpha-synuclein clumps developing in the substantia nigra, causing degeneration of dopamine-producing nerve cells. Symptoms include typical Parkinson's rigidity, tremor, gait alterations, and slowed movement (Alzheimer's Association, 2018f).

Mixed Dementia has more than one cause. Most commonly, AD is combined with Vascular Dementia; next most common is AD with Dementia with Lewy-Bodies, or all three types may be combined. Nearly half of all older people with dementia suffer from mixed dementia (Alzheimer's Association, 2018f).

Frontotemporal Dementia (FTD) (Pick's disease) is a group of disorders with progressive nerve loss in the frontal and temporal lobes.

- *Behavior variant frontotemporal dementia (bvFTD)* shows significant alterations in personality, conduct, and interpersonal relations, most commonly developed between the 50s and 60s, but ranges from the 20s to the 80s.
- *Primary progressive aphasia (PPA)* affects speaking, writing, and comprehension. Onset is usually before age 65, but can be later. Subtypes are *semantic variant PPA*, in which the patient can neither understand nor create words in a spoken sentence, and *nonfluent/agrammatic variant of PPA*, where speaking becomes ungrammatical and hesitant.
- *Disturbances of motor function* include amyotrophic lateral sclerosis; corticobasal syndrome (arms, legs are stiff and uncoordinated); and progressive supranuclear palsy with posture changes, difficulty ambulating, and muscle stiffness.
- In the age 45–65 range, bvFTD and PPA are as common as early-onset AD. However, over age 65, these types are much less common than AD (late onset). An estimated 50,000 to 60,000 people in the United States between ages 45 and 65 suffer from one of these two variants of FTD (Alzheimer's Association, 2018b). Psychiatric symptoms are common, but AD drugs do not appear to be effective for symptoms. Serotonergic antidepressants can improve psychiatric symptoms (Buoli et al., 2017).

Other Dementias are less common, such as the rare, fatal Creutzfeldt-Jakob (mad cow disease); Huntington's disease; and normal pressure hydrocephalus. Wernicke-Korsakoff syndrome, a chronic memory disorder from severe thiamine deficiency, is most commonly seen with chronic and long-term alcohol abuse.

Screening: The Medicare Annual Wellness Visit mandates screening for cognitive impairment (Alzheimer's Association, 2018f). Mild cognitive impairment (MCI), diagnosed on screening tests, only affects episodic memory, without physical symptoms. All patients with gradual or new-onset memory issues, as well as other brain symptoms, should be assessed with one or more cognitive screening tests.

The most frequently performed test is the *Folstein Mini-Mental Status Exam (MMSE)*. The MMSE takes as little as 7 minutes and involves standard questions and tasks. A shorter version, termed the *mini-cog*, takes about 3 minutes. It includes a three-item recall, and a clock face drawing with the time of 10 minutes after 11:00 (Seeley & Miller, 2016).

A more sophisticated test is the *Montreal Cognitive Assessment*, a 30-point test that requires about 10 minutes to administer, even including animal pictures for patients to identify (free at http://www.mocatest.org).

How is AD Diagnosed? Laboratory tests used to rule out other disorders that mimic dementia include complete blood cell count and differential; serum electrolytes, creatinine, blood urea nitrogen, fasting glucose, calcium, liver function tests, vitamin B12, thyroid-stimulating hormone, and freeT4. For some patients, HIV testing, syphilis testing, and a heavy metal screen can be useful.

Diagnostic imaging, including brain magnetic resonance imaging or a computed tomography scan without contrast, is commonly used to test new-onset memory issues to rule out cerebrovascular changes, tumors, and other structural abnormalities. Positron emission tomography (PET) with fluorodeoxyglucose provides a more sophisticated differentiation between AD and FTD. PET imaging with radiolabeled ligand for beta-amyloid may show positive evidence for AD. In patients older than 60, however, amyloid plaques may be present with MCI only, so the sensitivity of this test becomes more limited. PET imaging for tau particles is in the experimental stage (Seeley & Miller, 2016).

In 2016, Medicare approved payment for brain imaging for amyloid protein through a unique PET scan. Researchers are studying an experimental infusion (monthly) of aducanumab, a drug that breaks down amyloid. People with higher risk, cognitive impairment, or AD particularly are encouraged to exercise, maintain a heart-healthy diet and weight, and keep stimulating their brains with challenging work, play, and games. Early diagnosis and treatment appear to slow the progress of the disease.

—Mary A. Helming, PhD, APRN, Contributing Editor

GOD NEVER FORGETS Reaching Persons with Dementia

By Elizabeth M. Long

Dementia does not alter one's need for expressing faith. Spirituality and religion can be important to quality of life for persons with dementia. Spiritual needs can be overlooked when a patient has memory loss and is unable to communicate understandably (Jolley & Moreland, 2011; Ødbehr, Kvigne, Hauge, & Danbolt, 2014). When caring for someone with dementia, it is imperative to find avenues to connect and allow expression of faith. Potential activities might include prayer, reading Bible verses, and sharing music that has meaning or represents religious history for the individual.

GOD NEVER FORGETS

Not being able to verbalize with someone with dementia can be frustrating, and even frightening. However, we can remember the promise that memory issues, aggression, forgetting, the inability to communicate, and beta amyloid and tau proteins or neurofibrillary tangles in the brain do not affect God's grace or ability to sustain. Romans 8:28-29 (NIV) reminds:

> For I am convinced that neither death nor life, neither angels nor demons, neither the present nor the future, nor any powers, neither height nor depth, nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord.

How do we reach the spiritual side of someone with dementia? How can we help someone access faith? Is there a way to help someone find comfort and express faith, even when in the last stages of dementia?

Research points to the benefits of individualized musical playlists for dementia patients, who are no longer able to effectively interact with others. Individualized music can decrease agitation and increase social interaction and communication in patients with dementia (Long, 2016; Thomas et al., 2017), especially in the final stages.

MUSIC & MEMORY™

Over the last 2 decades, researchers have reported physical and psychological benefits of music interventions across the lifespan, in various disease states, and in diverse healthcare settings. Examples include autism, palliative care, traumatic brain injury, anxiety, developmental disabilities, and motor disorders, occurring in nursing homes, homes, hospitals, and other outpatient settings (Gutiérrez & Camarena, 2015; Long, 2016).

Music & Memory™ (2018) utilizes an iPod® shuffle, iTunes® music cards, and headphones to deliver an individualized music playlist. The key is to find music that has meaning to the individual. Music & Memory™ should be distinguished from *music therapy* that involves a certified music therapist.

In Southeast Texas, a group of 50 patients who resided in certified long-term care facilities were introduced to Music & Memory™. Local nursing students implemented the program, assessing music tastes from patients, families, and friends. Genres included country, gospel, Christian, rock and roll, jazz, and zydeco. Using music samples to assess preference, 70% of patients responded to gospel and Christian music as enjoyable.

Students were asked to describe patient reactions to music and their observations about interactions. They noted that when gospel or Christian music was played, many patients had a positive reaction—a nonverbal patient smiling, tapping hands or feet to the music, or relaxing, if agitated. Some patients clapped to the music, smiled, or sang along with familiar Christian hymns. One individual who had been verbally noncommunicative for months, when hearing hymns shouted out, "Yes, Lord!" smiling broadly and holding his daughter's hand.

> **A tone of promise and hope must never falter in nurses' shared journey with people with AD.**

In at least three instances, patients who were formerly nonverbal or incoherent began to sing hymns or other gospel music, word-for-word, and reminisced about memories. To one family whose loved one had not spoken in months, watching their loved one burst into song was moving. Several patients who had required medications for agitation and combative symptoms had their dosages reduced or discontinued after participation in the Music & Memory™ program.

Another benefit of this program is economic feasibility. The price is approximately $60 per individual. For a small financial investment, a patient lost to dementia has the potential to reconnect with their environment, faith, and loved ones in a meaningful way.

IMPLICATIONS: BEING THE PATHWAY

We can be God's hands and feet by providing a pathway for dementia patients to express faith. Music & Memory™ is an intergenerational opportunity for faith communities to become involved by:

1. Developing individualized playlists for persons with dementia;
2. Adopting a long-term care facility and implementing a Music & Memory™ program;
3. Working with an already certified facility;
4. Holding an iPod® and/or iTunes® card drive and donating items;
5. Donating funds or obtaining grants for care facilities.

As patients progress through AD and other dementias, many physical and psychosocial attributes diminish or disappear. However, faith and the need to connect with God remain. Individualized music playlists are a way to reconnect someone with their faith history and serve as Christ's hands and feet.

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Disclosure Statement: The authors and planners have disclosed that they have no financial relationships related to this article.

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