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***By Karen Gilbert, DNP, MS, RN, CDP***



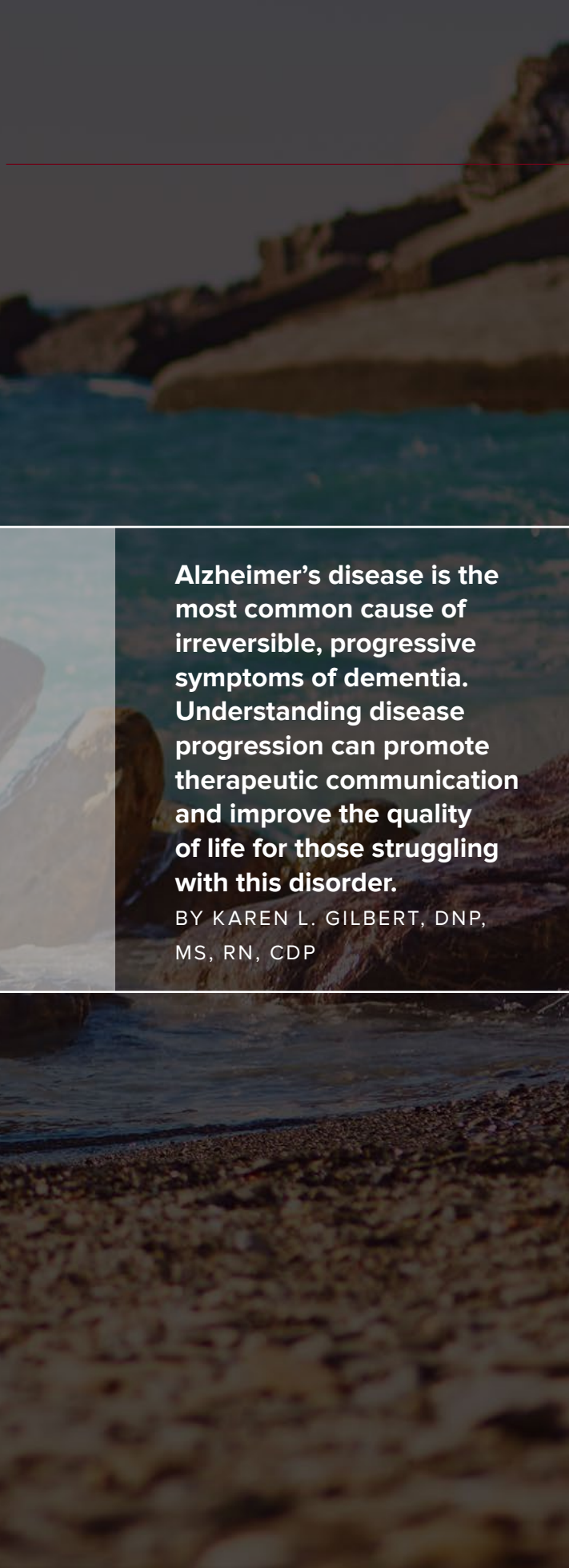
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# Managing Alzheimer's Disease as a Chronic Illness: **Reaching and Honoring the Person Within**







**Alzheimer's disease is the most common cause of irreversible, progressive symptoms of dementia. Understanding disease progression can promote therapeutic communication and improve the quality of life for those struggling with this disorder.**

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With almost six million known patients in the United States and an aging population suggesting that this number may reach 14 million by the year 2050, understanding Alzheimer's disease (AD) as a chronic illness is critical to refining concepts of care (Alzheimer's Association, 2020, p. 406). Integrating AD within the realm of chronic disease is not as uniform as one might believe. Notwithstanding an estimated 44 million people with AD worldwide, the World Health Organization does not include AD in its list of "main" chronic illnesses (World Health Organization, 2005, p. 35). Many millions more people are touched by this devastating condition, including spouses and caregivers, often without the knowledge and support they need to make the most of this time. Professionals can play a vital role in assisting families through the various challenging stages of AD, provided they have an understanding of its aspects.

The protein pathologies of beta amyloid plaques and tau tangles in the brain of affected individuals were identified by Dr. Alois Alzheimer back in 1906.

However, general recognition of Alzheimer's disease came far later. Early on, patients and caregivers struggled through the identification of AD as a category of mental illness, with the associated stigma. That changed in 1983 when President Ronald Reagan declared November "Alzheimer's Awareness Month" in the United States, and then announced in 1994 that he had the condition via a poignant open letter to the American people. Here is a revealing excerpt from that letter:

In opening our hearts, we hope this might promote greater awareness of this condition. Perhaps it will encourage a clearer understanding of the individuals and families who are affected by it.

At the moment I feel just fine. I intend to live the remainder of the years God gives me on this earth doing the things I have always done. I will continue to share life's journey with my beloved Nancy and my family. I plan to enjoy the great outdoors and stay in touch with my friends and supporters.

Unfortunately, as Alzheimer's disease progresses, the family often bears a heavy burden. I only wish there was some way I could spare Nancy from this painful experience. When the time comes I am confident that with your help she will face it with faith and courage (Ronald Reagan Presidential Library, 1994). —*Ronald Reagan*

With his usual gift for words, the Great Communicator referenced several aspects of the experience of Alzheimer's disease: the need for greater awareness and understanding, the desire for how he wished to live through his remaining years, and the burden borne by families. Reagan touched on the substance of the human condition, the innate needs that motivate and frame our lives. To this day, greater awareness, education, and understanding are critical to overcoming stigma and the potential isolation of patient and caregiver (Alzheimer's Association, n.d.a; Campbell, 2004).

## The Progression of Alzheimer's Disease

### EARLY STAGE

The Centers for Disease Control and Prevention (CDC) define chronic disease as "conditions that last one year or more and require ongoing medical attention, or limit activities of daily living, or both," and appropriately include AD on this list (Centers for

Disease Control, 2020). Alzheimer's is a fatal disease as well as a chronic one. Life expectancy from time of diagnosis can range from four to twenty years, heavily influenced by the stage of disease at diagnosis and the number, type, and management of other chronic (comorbid) conditions (Alzheimer's Association, n.d.b).

Though the symptomatic stages of AD are typically described as early, middle, and late, there is tremendous variation in how patients manifest symptoms. The disease typically begins with a noticeable deficit in short-term memory resulting from the disease's influence on the hippocampus, the structure within the brain's temporal lobe with a vital role in memory (Sinha, 2019). Impairment in short-term memory results in the inability to retain new information. As the disease progresses, each patient's presentation is unique due to the variable rate and pattern of progression of disease throughout the brain.

### MIDDLE STAGE

Symptoms intensify in middle-stage disease and may now include severely impaired short-term memory. Difficulties with language and longer-term memories start, along with mood swings, agitation, irritability, and the inability to make decisions or problem solve. Physical challenges include difficulty with transfers and ambulation. Fine motor skills may become impaired, as becomes evident in changes in handwriting, difficulty with fastening clothing or shoes, or using eating utensils. In this long middle stage, symptoms differ from patient to patient as the different lobes of the cerebrum are affected with varying severity. Deficits become more obvious and problematic for the patient and increasingly challenging for the caregiver.

The basic functions of the various lobes illustrate how symptoms can vary. For example, *frontal lobe* impairments may include challenging behaviors, inappropriate language, failure of abstract thinking and problem-solving, and an inability to identify right from wrong. *Temporal lobe* damage may manifest as increasing memory failure, particularly episodic memory, which is associated with specific events. Word-finding difficulties may emerge. The *occipital lobe* processes visual input, and impairment here may result in an inability to interpret what the patient sees. The *parietal lobe* has various functions in our perception of sensory inputs such as touch, pressure, pain, and integration of visual input. Damage to this area can also impair writing and math skills (Hill, 2019).

Interactions with the patient will reveal specific deficits and challenges. In the early stage of symptomatic disease, deficits may be subtle; patients aware of emerging memory failure may try to compensate, decline help, and resist evaluation. They may feel anxious, concerned about the potential stigma associated with symptoms of dementia and a loss of independence.

As the middle stage further evolves, the patient will need assistance with bathing, dressing, preparing meals, and at some point, will not be able to be alone safely for part, or all, of the day. Though middle stage Alzheimer's usually lasts eight to ten years, some patients may spend upwards of fifteen years progressing through this period.

#### **LATE STAGE**

In the late stage, patients are completely dependent on others, and may be bedbound. Damage to the cerebellum impairs balance, equilibrium, and coordination. The eventual damage to the brainstem may impair swallowing, resulting in a high risk for aspirating food and/or fluid into the lungs and resulting in life-threatening pneumonia. The death of the patient is often attributed to such a pneumonia or another of the patient's chronic conditions. AD's damage to the brain stem also impacts regulation of heart rate, breathing, blood pressure, and consciousness. Alzheimer's disease is currently recognized as the sixth-leading cause of death in the United States, fifth for those over age sixty-five (Alzheimer's Association, 2020, p. 407).

### **Clinical Considerations in Caring for the Person with Alzheimer's Disease**

Managing and monitoring comorbid conditions, such as diabetes, hypertension, congestive heart failure, and chronic respiratory diseases, is critical throughout all three stages, but particularly as the disease progresses. As cognitive impairment worsens, patients may not be able to self-administer medications reliably or correctly; they may be unable to recognize or verbalize symptoms of an underlying condition that is no longer well-managed. When underlying conditions are poorly controlled, cognition may worsen further. Throughout the neurocognitive disease process, well-managed comorbidities optimize cognition and the patient's overall well-being.

There is a distinction between the course of AD and other common comorbidities affecting older adults. While diabetes, heart disease, chronic lung disease, and even many cancers may remain relatively stable over a period of many years with the oversight of

health professionals and compliance with prescribed regimens, AD manifests differently. With no cure and no substantive disease-modifying treatment, AD progresses steadily throughout its stages, though some patients may seem to plateau at certain junctures with a temporary reprieve from discernible progression (Nelson & Tabet, 2015, p. 194).

### **The Art of Caring for the Person with Alzheimer's Disease**

These are the clinical considerations of the chronic, progressive, irreversible nature of Alzheimer's disease, its progression rooted in science yet subject to the art of appreciating each patient's unique course. Indeed, the art component is critical to rendering compassionate, therapeutic care, demonstrating beneficence for the patient and optimizing each patient's distinctive experience.

Diabetes, heart conditions, chronic lung diseases, and other chronic health challenges have measurable indicators: laboratory and other diagnostic tests. Such medical evaluations provide objective measures of the stage and/or status of the disease at any given time and guide medical decision making and clinical management. These measures, along with evidence-based clinical practice guidelines (National Center for Complementary and Integrative Health, 2020) for diagnosing and treating such conditions, are the substance of established, well-recognized, and reliably employed medical principles for these common conditions.

However, Alzheimer's is a disease with much variation in presentation and progression, and no specific set of medical principles to add predictability. Each patient's history, with its lifetime of experiences, is the foundation for an individualized approach. The goal of this method should be honoring the life lived while promoting dignity, security, and comfort against a backdrop of declining function and uncertainty.

### **Social Aspects: Meeting Needs**

Maslow's hierarchy suggests that basic physiological and physical needs (food, water, safety, security) must be satisfied in order to address the higher psychological needs. These higher needs include the desire for relationships, the want to belong, the desire to engage in social interactions that foster friendship, trust, acceptance, affection, intimacy, and love, and which promote self-esteem (McLeod, 2020). Ultimately, self-fulfillment needs can be met: the need to have purpose, to achieve one's potential, and to have a sense of personal success (McLeod, 2020).

Special attention must be paid to meeting these

needs; Alzheimer's interferes with their achievement. As AD progresses, patients lose the ability to navigate both the basic and psychological needs in the hierarchy. Advancing deficits promote isolation, perversely limiting those very engagements and interactions that foster self-esteem, sense of purpose, and accomplishment. These effects may in turn accelerate cognitive decline. At the same time, the person within still has all these needs. The "managing" of Alzheimer's disease relies on ensuring that basic needs continue to be met, and on recognizing and nurturing the accessible memories, abilities, and interests that reflect the patient's expression of self-fulfillment. The patient can be protected from "empty" days by using his or her remaining skills and interests to define quality of life throughout the AD journey (Manson, Ciro, Williams, & Maliski, 2020). However, there is no single formula, no single set of recommendations, no single psychosocial "prescription" for honoring the patient's unique expression of his or her human condition or for navigating the progressive challenges posed by AD.

Knowing how the patient lived, and more significantly, how he or she *wanted to continue to live*, are integral to optimizing well-being as AD progresses to its most debilitating late stage. To the greatest extent possible, daily activities should align with remaining faculties and draw upon the patient's unique and special history. It is this history that may remain retrievable in long-term memory until late in the disease process. These long-term memories may not only bring smiles but can inspire a sense of well-being. With short-term memory failure and the inability to capture, interpret, retain, or act upon new information, patients with AD may spend a significant amount of time in an earlier era, a world better understood, an environment in which they perceive they have better control.

Validation is often the preferred communication strategy. When we validate, we do not argue or correct; rather, we honor the patient's perceptions, the patient's reality, understanding that the patient is more "successful" in his/her perceived world, the world best remembered. As professionals and caregivers, we learn that it is more important to be an empathetic, accepting listener, entering the patient's world, than it is to be "right."

Filmmaker Deborah Hoffman, in her Academy Award-nominated documentary about her mother's life with AD, *Complaints of a Dutiful Daughter*, expresses the essence of validation when she realizes that she cannot, and should not, correct her mother's (mis)perception of the current month. Instead, Hoffman says with conviction, "What does it matter if she

thinks it's April?" (POV,1995). Similarly, we can validate the patient asking about a long-deceased spouse, redirecting the discussion to a therapeutic reminiscence. In contrast, imagine "reminding" the patient that a beloved spouse died years ago. This becomes a new trauma, a new source of grief each time the patient is so reminded.

Quality of life for the patient with AD will rely heavily on the extent to which the positive aspects of the world he or she once inhabited can be brought forth and incorporated into daily experience. The following considerations may inform a therapeutic day:

- Varying impacts on memory may have the patient unable to recall things recently experienced (failure of episodic short-term memory) but able to successfully complete the puzzles in the daily newspaper (a retained procedural memory function).
- Can the patient still read? Know the person's preferences: fiction, non-fiction, history, sports, inventions, magazines, etc.
- Does the patient find purpose and feel successful in caring for plants or for a pet, painting or drawing, sewing or knitting?

To the extent that a patient with AD can exercise remaining skills and abilities, self-esteem and purpose can be enhanced, instilling quality in the day and redirecting focus away from that which the patient can no longer do or control.

At some point, the patient living alone may no longer be safe to do so, or the needs of a patient living with family members may exceed the physical and/or financial resources of the family. When placement into an assisted living community or skilled nursing facility is considered, appreciation of how the patient lived and how he or she wished to continue living will be critical in transitioning to the new environment. The extent to which the facility can mirror the patient's best-remembered adult life will likely determine adjustment to the new setting. Can the facility honor residents' familiar sleep and wake cycles, their preferred type and time for bathing, and allow residents to have favorite, familiar toiletries in the room? Does the facility's schedule of activities afford types of engagement that stimulate interest and optimize remaining skills? Will dietary preferences be honored?

In a study conducted in five Norwegian nursing homes, Næss, Fjær, and Vabø (2016) proposed "assisted self-presentation" as the art of discovering and promoting "the habits, preferences and tastes of



individual residents” as well as promoting residents’ “personal narratives” (pp. 155, 159) in order to preserve dignity, and residents’ “sense of self” (p. 154). How the patient would want to live becomes the most critical consideration when the AD or a comorbid condition becomes terminal.

## Advance Directives

Although an advance directive can detail one’s wishes for instituting or withholding specific medical treatments and identify a healthcare surrogate should one become unable to speak for one’s self, the CDC reports that only about one-third of Americans have prepared this document (Centers for Disease Control, 2018). Once the cognitive impairment of AD or a related neurocognitive disorder prevails, the opportunity for the patient to exercise this expression of autonomy is lost. Critical decisions are now left to the appropriate surrogate, whose authority is generally based in state law.

Without the patient’s advance directive, it is incumbent upon those of us in caring and advocacy roles to learn as much as we can about how the patient lived, what was important to that person, that which gave purpose, brought a smile, and constituted a “good” day. These individual preferences should inform decisions regarding life-sustaining treatments, particularly when it is clear that such treatment will only sustain, rather than improve, quality of life.

Even as we find effective ways to turn formerly life-threatening diseases into manageable chronic conditions with innovative medical treatments, Alzheimer’s disease continues to frustrate such efforts. With disease-modifying treatments still elusive and no cure on the horizon, we remain ever-challenged to see beyond the disease, to grasp the importance of preserving the patient’s safety and security, dignity and integrity, welfare and well-being, with approaches focused on reaching and honoring the dynamic person within. •CSA



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