

PERSPECTIVE

Navigating late-stage dementia: A perspective from the Alzheimer's Association

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Email: mmoreno@alz.org**Abstract**

Alzheimer's disease (AD) is the most common cause of dementia, a general term for memory loss and decline in other cognitive abilities enough to interfere with daily life. AD accounts for 60% to 80% of dementia cases. The late stage of AD tends to be the shortest stage and, on average, lasts 1 to 2 years. As this stage of the condition progresses, it requires continuous intensive long-term care and around-the-clock intensive care. The Alzheimer's Association stands firm in its commitment to supporting individuals living with AD and other dementia, their care partners, and their health-care providers as they navigate treatment and care decisions across the continuum of the disease. This article is a direct response to recently published works that run counter to the Association's viewpoint. It outlines the Association's perspective on crucial factors for consideration during late-stage dementia care, including advanced directives, palliative care, nutrition, and legal considerations. It explores diverse perspectives from the field, differing from the Alzheimer's Association's stance. Last, it underscores resources available through the Alzheimer's Association, aiming to present a comprehensive perspective on late-stage care for support and assistance to all involved.

1 | INTRODUCTION

According to the Alzheimer's Association 2023 *Alzheimer's Disease Facts and Figures* report, an estimated 6.7 million Americans age ≥ 65 are living with Alzheimer's disease (AD).¹ Projections indicate that this number will more than double by 2050. While it is crucial to develop treatments and strategies to decrease the incidence of AD and related dementia, it is equally important to prioritize care and support for individuals living with dementia, including those in the late stages.

In late-stage dementia, individuals often undergo profound cognitive decline, experience marked functional impairment, and exhibit notable behavioral changes. These changes include (1) difficulty eating and swallowing, (2) the need for assistance in walking and eventual

inability to walk, (3) requiring full-time assistance with personal care, and (4) vulnerability to infections, especially pneumonia. This stage of the disease typically lasts ≈ 1 to 2 years, necessitating specialized and intensive around-the-clock care to maintain the individual's quality of life. Caregivers, who play a crucial role in all stages of the disease, become particularly important in the late stage of AD as individuals often lose the capacity for verbal communication and ability to express their needs. Research suggests that during this period, some core elements of their identity endure, supporting the possibility of maintaining connections throughout the advanced stages of the disease. This phase calls for individuals to predominantly perceive the world through their senses, allowing for the expression of care through touch, sound, sight, taste, and smell, even more so than in other stages of the disease.²

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Caregivers often find decision making about individuals living with dementia challenging and nuanced. To make informed decisions on behalf of someone with AD, caregivers need first to understand the needs, wants, desires, and hopes of the person and also to understand the factors that influence decision making and when these factors should be considered throughout the progression of the disease.

The Alzheimer's Association is a multifaceted global organization that supports evidence-based research and serves as a dedicated patient advocacy group. The Association firmly supports individuals living with dementia, their care partners, and their health-care providers as they navigate treatment and care decisions across the continuum of the disease. This article responds directly to two papers published in *Alzheimer's & Dementia: Diagnosis, Assessment and Disease Monitoring (A&D DADM)*. One article is entitled "Can an Effective End-of-Life Intervention for Advanced Dementia Be Viewed as Moral?" by Stanley A. Terman,³ and the other is "Timely dying in dementia: Use patients' judgments and broaden the concept of suffering" by Stanley A. Terman, Karl E. Steinberg, and Nathaniel Hinerman.⁴ These articles and their accompanying responses discuss many points that are in direct disagreement with the position of the Alzheimer's Association. This article explicitly highlights the current positions of the Alzheimer's Association regarding advanced directives, palliative care, nutrition, and legal considerations.

2 | END-OF-LIFE CARE

Initiating conversations surrounding end-of-life care and treatments early in the disease when the individual living with AD can express their desires is important. Given the complexity of decisions that families may confront when making choices for individuals affected by AD or related dementia, it becomes imperative for those living with the condition to proactively designate someone to act on their behalf during later stages of the disease. Ideally, individuals living with dementia should proactively establish advance directives, clearly outlining their preferences for end-of-life care.

To plan effectively for the advanced stages of dementia, particularly when the individual cannot make decisions independently, individuals should draft a durable power of attorney for business and financial decisions, create estate wills, and establish living wills that articulate their wishes concerning end-of-life care and the use of life-support systems. Recognizing the complexities surrounding end-of-life decisions in the context of dementia, the Alzheimer's Association provides valuable resources for patients and caregivers.⁵ These resources offer guidance on advocating for care based on the expressed wishes of the individual with dementia, considerations involved in refusing, starting, limiting, or terminating medical treatments, including treatments surrounding feeding and hydration, facilitation of care focused on comfort, and assistance in arranging for a brain autopsy.

In the absence of advanced directives or if certain aspects remain unclear, caregivers find themselves making decisions based on their

understanding of the individual's likely personal desires. All end-of-life decisions must align with the individual's values, respecting their wishes and upholding their comfort and dignity. Legal provisions vary by state and country, but without advance directives, a spouse or adult child might be granted the authority to decide on discontinuing medical treatments.

Establishing open communication and proactively discussing these matters early in the disease can significantly alleviate the burden on families and caregivers when making difficult decisions without clear directives. Individuals living with dementia possess the legal right to control, refuse, or halt medical treatments, typically conveyed through advance directives formalized in legal documents specifying desired medical care when the person no longer can decide, along with a designated decision maker. Therefore, establishing advance directives while the individual still retains mental and legal capacity and the ability to make sound judgments and decisions required for signing official documents or managing medical and financial affairs is imperative.

3 | PAIN AND WELL-BEING OF INDIVIDUALS IN LATE-STAGE DEMENTIA

The Alzheimer's Association supports decisions to forgo hospitalization and invasive treatments, including cardiopulmonary resuscitation and artificial nutrition and hydration, in favor of palliative and comfort care in a person's residence (home or care facility). Palliative care is a comprehensive, multidisciplinary approach aimed at alleviating pain and enhancing the overall quality of life by addressing an individual's physical, mental, social, and spiritual well-being. It specifically targets relief from the symptoms and stress of a serious illness. Practitioners can administer palliative care at any stage of a disease or condition, whether terminal or not. This includes late-stage dementia, during which the focus is on reducing the pain and suffering of the individual. While many practitioners advocate for palliative care for individuals with late-stage dementia, there are few research-driven studies on this subject.^{6,7} Nevertheless, it is essential to highlight that the palliative approach is rooted in person-centered care, emphasizing preserving the individual's values and identity.⁸ The Alzheimer's Association supports the decision to implement palliative care and expresses the hope for increased research studies in the future, specifically focusing on this compassionate care approach.²

Palliative care plays a crucial role in addressing pain, particularly in recognizing that individuals with dementia may undergo pain or discomfort without fully expressing it or responding in ways commonly associated with pain. This care is beneficial at any point in the illness and can be initiated after a diagnosis. On the other hand, hospice care emphasizes providing care and comfort and enhancing the quality of life for individuals nearing the end of their life journey. While a recent article entitled "Timely dying in dementia: Use patients' judgments and broaden the concept of suffering" proposes that expressed agitation results from an inability to convey pain properly,⁴ it is essential to

note that even individuals in later stages can communicate discomfort or pain through sounds or facial expressions. The Alzheimer's Association advises caregivers that dementia-related behaviors, including agitation, serve as a form of communication. Caregivers need education on approaches to discern and understand what individuals with dementia are trying to communicate, predominantly when expressed non-verbally.^{2,5}

Another point discussed in the article titled "Timely dying in dementia: Use patients' judgments and broaden the concept of suffering" refers to how caregivers' mental health and well-being are impacted by a "loved one's suffering."⁴ While there are many challenges in caring for an individual living with dementia, caregivers often feel honored to care for their loved ones. In 2021, the Alzheimer's Association conducted a survey to gain insights into the caregiving experience, revealing that many family members and friends find rewards in providing care, which can counterbalance the associated stress. The survey results, outlined in the Alzheimer's Association's *Alzheimer's Disease Facts and Figures 2021 Special Report on Race, Ethnicity, and Alzheimer's in America*,⁹ emphasize that while nearly two thirds of caregivers (64%) acknowledge the stress of their responsibilities, an overwhelming majority (92%) also describe caregiving as a profoundly rewarding experience. To enhance the caregiving journey, the Alzheimer's Association advocates for a person-centered approach, encouraging caregivers to engage individuals in activities that bring them joy, such as playing favorite music or reading beloved books, fostering a sense of connection.²

The Alzheimer's Association believes that various medical conditions, medication interactions, or situations that hinder cognitive function can lead to anxiety and agitation, especially in the later stages of AD. Ultimately, individuals with dementia are undergoing a significant loss in their capacity to process new information and stimuli directly stemming from the impact of the disease. The Alzheimer's Association recommends always trying non-pharmacological approaches before resorting to drug treatments. However, if that route does not work, caregivers could consider talking to their loved one's doctor about using brexpiprazole (Rexulti), a recently US Food and Drug Administration-approved atypical antipsychotic for agitation associated with dementia due to AD.¹⁰

An article titled "Response to Stanley Terman: Too Little, Too Late" in *A&D: DADM* presents a perspective advocating for euthanasia options for individuals in the early stages of AD or related dementia.¹¹ It is worth noting that euthanasia is legally permitted in the Netherlands (where the article's authors live) when specified in advance directives. However, research indicates a hesitancy among certified elderly care physicians to engage in this practice.^{12,13} This viewpoint on euthanasia disagrees with the position of the Alzheimer's Association.

It is equally crucial to extend support to individuals recently diagnosed with dementia, as this period often brings confusion and numerous questions. The Alzheimer's Association offers comprehensive assistance throughout the entire disease trajectory and can provide

resources from the initial diagnosis. It is imperative to explore all available avenues during this phase of the disease when treatments and clinical options are most accessible.

4 | ASPECT OF CARE TO CONSIDER—NUTRITION

During late-stage dementia, individuals reach a phase during which self-feeding becomes challenging, necessitating feeding assistance and supervision. The disease progression gradually leads to the loss of neurological control over the oral and swallowing phases of eating and drinking, representing an inevitable and expected course of AD. Numerous factors contribute to individuals ceasing to eat independently, and it is important not to automatically equate this inability with "severe suffering," as in a recent article titled "Can an Effective End-of-Life Intervention for Advanced Dementia Be Viewed as Moral?"³ Though unable to feed themselves, many individuals accept food and hydration, particularly when it aligns with their preferences.

While the individual cannot self-feed, alternatives must be considered. In 1981, the percutaneous endoscopic gastronomy (PEG) tube procedure was designed to safely deliver nutrition and hydration to individuals who were unable to swallow. Research has aimed to determine whether this method surpasses the benefits of traditional careful hand feeding. Studies indicate that in contrast to hand feeding, tube feeding via PEG or nasogastric tube presents no advantages.^{14,15} The Alzheimer's Association states that research evidence supports no medical benefit from feeding tubes in advanced dementia and that feeding tubes may actually cause harm in the advanced stages of AD.¹⁶

There is a need for more caregiver education about the pros and cons associated with life-sustaining treatments, such as feeding tubes. Initiating conversations early on regarding the use of feeding tubes, hydration, and other life-sustaining interventions is crucial. This ensures that both the caregiver and the family are aware of the preferences of the individual living with dementia. Additionally, this information can help caregivers and families feel more confident making these difficult decisions.

Alternatively, hand feeding can provide more relationship interactions with caregivers. Despite the challenges, joy and pleasure can still be experienced through the act of eating, particularly when the caregiver feeding them is attuned to the individual's likes and dislikes. The Alzheimer's Association emphasizes that careful hand feeding offers the highest quality of care and should be offered to all individuals with advanced AD who can competently and comfortably handle oral feeding. Concerted efforts are called for to educate and support professional and family caregivers in techniques of careful hand feeding. At the same time, the Alzheimer's Association states that it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube when the individual with AD or dementia is no longer able to receive food or water by mouth.¹⁶

5 | LEGAL CONSIDERATIONS FOR END-OF-LIFE CARE

The Alzheimer's Association actively advocates for choices that improve the overall quality of life for those affected by dementia. Enhancing the quality of life for individuals with dementia and their families crucially depends on end-of-life care, which includes palliative and hospice care. Unfortunately, discussions about this care often occur belatedly during the disease, resulting in missed opportunities for comprehensive support. The concerning findings from the National Hospice and Palliative Care Organization (NHPCO) report underscore the brevity of hospice care for a substantial proportion of Medicare beneficiaries in 2018, with 53.8% receiving care for ≤ 30 days and 27.9% for ≤ 7 days—insufficient periods for optimal benefit.¹⁷

A November 2023 *New York Times* article discusses the urgent need for a more robust and cohesive elder care system in the United States.¹⁸ The article emphasizes the challenges individuals living with dementia and their caregivers face in maintaining independence, citing issues due to health-care systems and the overall costs associated with long-term medical care. It states, “Millions of families are facing such daunting life choices—and potential financial ruin—as the escalating costs of in-home care, assisted-living facilities, and nursing homes devour the savings and incomes of older Americans and their relatives.” The Alzheimer's Association stresses the importance of improving care and support and actively advocates for change. However, a recent article entitled “Can an Effective End-of-Life Intervention for Advanced Dementia Be Viewed as Moral?” raises concerns about the rising number of individuals living with dementia, labeling it an “impending dementia tsunami” and pointing to potential challenges for the health-care system. The authors even contemplate the possibility of politicians adopting stringent measures, posing a threat to individual rights and the risk of national dementia-driven medical bankruptcy.³ These views are against the stance of the Alzheimer's Association. Decisions should be based on enhancing quality of life. Cost and fear about the systemic challenges of the US health-care system should not be deciding factors.

Navigating the intricate landscape of end-of-life care for individuals with dementia requires addressing critical issues such as the timing of discussions, the brevity of hospice care, and the financial considerations that often shape decisions. It is imperative to achieve a delicate equilibrium between legal safeguards and individual desires to foster a holistic and ethically sound approach to end-of-life care in the context of dementia. Though, as previously discussed, it is ethical to withhold nutrition and hydration artificially administered by vein or gastric tube when the individual with AD or dementia is no longer able to receive food or water by mouth, it is essential to distinguish between withholding treatment and assisted suicide. The decision to refuse or withdraw treatment, such as tube feeding, antibiotics, or cardiopulmonary resuscitation, does not constitute assisted suicide (euthanasia). Limiting treatments allows the disease to follow its natural course while prioritizing the person's comfort and dignity. Even if aggressive medical treatment is declined or ceased, the care team must remain commit-

ted to delivering excellent physical and emotional care, ensuring the individual is pain free.⁵

6 | ALZHEIMER'S ASSOCIATION RESOURCES ACROSS THE DISEASE SPECTRUM

The Alzheimer's Association provides a wealth of resources to support and empower caregivers navigating the challenges of caring for individuals with AD and other dementia. One of the key offerings is the comprehensive website at [alz.org](https://www.alz.org), a hub of information and guidance covering various aspects of caregiving. Caregivers can access educational materials, including articles and guides that offer insights into understanding dementia, managing symptoms, and enhancing the quality of life for the individual living with dementia and the caregiver (<https://www.alz.org/help-support>). The Alzheimer's Association also organizes support groups, either in person or online, creating a space for caregivers to connect, share experiences, and gain emotional support (<https://www.alz.org/help-support/community/support-groups>). There is also an online platform called ALZConnected (<https://alzconnected.org/>), which is a free community for individuals living with dementia and those caring for them to post questions, offer support, and interact with others, reinforcing the idea that caregivers are not alone in their journey.

Furthermore, the Alzheimer's Association extends support through a 24/7 Helpline (1.800.272.3900), staffed by trained professionals ready to offer information, assistance, and emotional support. The Association also hosts workshops and training sessions, equipping caregivers with practical skills and strategies to cope with the evolving needs of individuals with dementia. These resources collectively form a robust support system, acknowledging caregivers' vital role in the well-being of those affected by AD.

7 | CONCLUSION

The Alzheimer's Association is dedicated to supporting individuals living with dementia, their caregivers, and health-care providers throughout the disease's continuum. Advocating for choices that enhance the overall quality of life for those affected by dementia, this perspective paper delves into the complexities of end-of-life care for those in the late stages of dementia. A comprehensive approach involving individuals with dementia, caregivers, and medical and legal professionals is essential for meaningful discussions and decision making. The hope is that by initiating conversations through this article and related papers, the field can elicit greater awareness that improves care for individuals with dementia.

Alzheimer's Association

The Alzheimer's Association forges partnerships with all those with a shared commitment to end AD and other dementia, including AD organizations around the globe; the National Institutes of

Health; the National Institute on Aging; universities; corporations; and the pharmaceutical, biotech, and device industries. With our broad partnerships, we are committed to transparency. The Alzheimer's Association received 1.06% of its total 2022 contributed revenue from the biotechnology, pharmaceutical, diagnostics, and clinical research industries. This and additional information can be found at www.alz.org/about/transparency.

The Alzheimer's Association owns the *Alzheimer's & Dementia* journal family, including *Alzheimer's & Dementia: Diagnosis, Assessment and Disease Monitoring (DADM)*, to which this article was submitted. The *Alzheimer's & Dementia* family of journals is an impartial means for the communication of divergent perspectives and the dissemination of current scientific and clinical research and advances in diagnosis and care, among the international community of scientists, clinicians, and caregivers. Papers published in the *Alzheimer's & Dementia* family of journals do not necessarily represent the policies or positions of the Alzheimer's Association.

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CONFLICT OF INTEREST STATEMENT

K. Clifford, M. Moreno, and C. M. Kloske are full-time employee of the Alzheimer's Association. Author disclosures are available in the [supporting information](#).

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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