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The Ethics Of Choosing To Die In An Age Of Alzheimer's Disease©

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Abstract

This Article examines ethical and legal questions presented when individuals in their last chapter of life decide it is time to die. Need they be terminally ill? If they have dementia, are they capable of making an end-of-life decision? Does it matter that today, for the first time in human history, our bodies can be kept alive for years by medicine, technology, and round-the-clock care long after we have lost all sense of who we are or who we have been? What moral language do we use when considering these questions? For answers, this Article examines ethical analyses published over the past four decades in the fields of medicine, law, ethics, and philosophy. Applying the normative ethics of Immanuel Kant and John Stuart Mill, insights from evolutionary biology and behavioral science, and experiences shared by those who have wrestled with these questions, this Article offers guidance on how healthcare professionals and society ethically respond to these questions.

I. Introduction

How does a person decide it is time to die? Does it matter how the person dies? Is there a legal right to die? What are the ethical obligations of healthcare professionals and others toward individuals seeking death? These are among the most difficult questions posed in the twenty-first century. Are we prepared to deal with them? Do we have the moral language to do so?

These questions are made more complex when those in their last chapter of life have Alzheimer's or a related dementia (ADRD). These diseases, unlike physical diseases, destroy a person's cognitive capacity long before they kill the body.[2] They impact millions of people.[3] Today, one out of nine individuals over sixty-five years of age has Alzheimer's, the most common form of dementia.[4] So do one out of three individuals over age eighty-five.[5] These numbers will explode in the years ahead as Boomers age and as the oldest of Gen-X and Millennials begin manifesting symptoms of dementia.[6]

End-of-life decisions, especially those made by people with dementia, raise emotional, spiritual, psychological, logistical, practical, and factual issues, all of which culminate into one fundamental question: Is it right or wrong to choose to die? This Article focuses on one end-of-life option: Voluntary Stopping Eating and Drinking (VSED) because of its special relevance to those with dementia. As this Article discusses, VSED is the only realistic and lawful end-of-life option for these individuals. Drawing on forty years of published academic literature on VSED, clinical data, ethical discourses throughout the centuries, insights from evolutionary biology and behavioral science, and personal stories of those who have wrestled with these issues, this Article provides a conceptual and practical framework to address these questions.

Part One presents a hypothetical situation that demonstrates ethical questions that may arise when a person with dementia chooses to VSED. Part Two provides clinical facts about dementia and VSED. Part Three provides an overview of ethical principles relevant to end-of-life decisions and to VSED. Part Four focuses on issues of medical ethics. Part Five addresses the ethical obligations of society regarding those who choose VSED.

II. Part One: A Hypothetical

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[2] *See Alzheimer's stages: How the disease progresses,* MAYO CLINIC (May 9, 2025), https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers-stages/art-20048448 [https://perma.cc/SP27-KU2Q] (describing brain decline due to Alzheimer's).

[3] *See Alzheimer Disease Statistics in US 2025,* WORLD DATA (Sep. 28, 2025), https://theworlddata.com/alzheimer-disease-statistics-in-us/ [https://perma.cc/BH9P-DSQ4] (presenting numbers in America affected by Alzheimer's).

[4] *See* ALZHEIMER'S ASS'N, 2025 ALZHEIMER'S DISEASE FACTS AND FIGURES 29 (2025) [hereinafter 2025 ALZHEIMER'S DISEASE FACTS AND FIGURES] (providing 2025 Alzheimer's statistics).

[5] *See id.* (explaining age ranges impacted by Alzheimer's).

[6] *Early-Onset Dementia and Alzheimer's Diagnoses Spiked 373 Percent for Generation X and Millennials*, BlueCross BlueShield, February 27, 2020, https://www.bcbs.com/about-us/association-news/early-onset-dementia-and-alzheimers-diagnoses-spiked-373-percent-generation-x-and-millennials; *See, e.g.,* Clare Ansberry, *When Elderly Parents Become Their Child's Caregiver*: WALL ST. J.A11 (April 15, 2025) (About 200,000 people in the U.S. between the ages of 30 and 64 are living with a form of dementia, the most common being Alzheimer's).

In 2017, Mr. P, a sixty-five-year-old male with no family history of Alzheimer's, began experiencing difficulty recalling words and names.[7] He sought evaluation at an academic medical center in an adjacent city. An experienced Alzheimer's physician gave Mr. P an extensive workup and diagnosed Mr. P with Alzheimer's disease (stage three of seven). The physician advised Mr. P that because of his physical health, active lifestyle, and cognitive reserves, Alzheimer's should not significantly impact his life for a number of years.

Upon receiving his diagnosis, Mr. P decided to revise his advance directive to include VSED. As a social worker with a thirty-year career working with intellectually disabled individuals, Mr. P had cared for and supervised care for, among others, individuals in the last two stages (stage six and seven) of Alzheimer's disease. From this experience, Mr. P had decided that if he were ever diagnosed with the disease, he would seek an end-of-life option before his Alzheimer's advanced to the last stages.

Mr. P talked with his family, his close friends, his doctors, and his lawyer. After investigating his end-of-life options, Mr. P learned that, realistically, VSED was his only lawful option. Three months after his Alzheimer's diagnosis, Mr. P executed a revised advanced directive that included VSED, specifying that he would commence VSED before he lost cognitive capacity.

Despite remaining physically active and socially engaged, Mr. P's Alzheimer's disease progressed quickly, possibly aggravated by prior severe, sports-related concussions. His visual-spatial abilities were significantly impacted. Within one month of diagnosis, upon his doctor's suggestion and prescription, Mr. P took the driving test for individuals with cognitive disease. He was unable to pass. Within several months of his diagnosis, Mr. P became unable to read, write, or work his computer, iPhone, or television remote. His balance worsened and he was unable to cycle, hike, or kayak—activities he had done almost every day of his life. He became unable to follow conversations and began to avoid social gatherings. Despite these losses, Mr. P's abstract thinking and focus remained intact. He was able to set and focus on goals, which his doctors said was likely because of cognitive reserves.

All of Mr. P's physicians were located at the academic medical center in the nearby city. Mr. P had one local physician in the town where he lived, which was fifty miles from the medical center. Mr. P saw Dr. X for minor ailments or routine checkups so that Mr. P could avoid trips to the academic medical center for such matters.

Mr. P had never discussed his Alzheimer's with Dr. X other than to tell Dr. X of his diagnosis. Mr. P's specialists at the academic medical center provided all aspects of Mr. P's medical care related to Alzheimer's. Even so, Mr. P provided his local physician with his updated advance directive that included VSED. As with his other physicians, Mr. P directed Dr. X's attention to the VSED provision and asked if Dr. X was supportive, to which Dr. X replied yes.

In February 2020, sixteen months after his diagnosis, Mr. P, aware that his Alzheimer's was progressing quickly and that his window of cognitive capacity was likely closing, met with his Alzheimer's physician. They conducted the pre-VSED assessments recognized as best practices (and subsequently, in 2023, set forth in the *Clinical Guidelines for VSED*).[8]

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[7] For the facts and quotations included in this hypothetical, *see* Pamela Bucy Pierson, A Hypothetical 1 (March 13, 2025) (unpublished manuscript) (on file with Suffolk University Law School Journal of Health & Biomedical Law). Facts in this hypothetical regarding Alzheimer's disease and VSED are discussed *infra* in this Article.

[8] S*ee generally* David Gruenewald & Greg Vandekieft, *Options of Last Resort: Palliative Sedation, Physician Aid in Dying, and Voluntary Cessation of Eating and Drinking*, 104 MED. CLINICS N. AM. 539, 539 (2020) [hereinafter *Options of Last Resort*] (recognizing best practices by palliative care experts);

Mr. P's physicians agreed that his Alzheimer's was progressing quickly. They determined that he had progressed through stage three, entered stage four, and was progressing into stage five. They agreed that his window of competence would close soon, and that if Mr. P did not commence VSED, he could lose the cognitive capacity to do so.

Mr. P's physicians made a referral to the hospice he had selected. Within days, Mr. P met with the hospice officials who conducted similar assessments of cognition, voluntariness, and suffering. The hospice officials stated that their hospice would admit Mr. P to home hospice on day two or three of his VSED as Mr. P weakened from lack of fluid and food, and they expected, he would then meet their admission standards.[9] The hospice officials requested that Mr. P notify any of his local doctors of his upcoming admission as a courtesy and pursuant to hospice policy.

A few days after meeting with the hospice admitting committee, Mr. P met with Dr. X per hospice's request and to thank Dr. X for their care over the years. Mr. P told Dr. X he had met with his Alzheimer's physicians and determined that because of the rapid progression of his Alzheimer's disease and the need to act while he was still cognitively capable, he would begin VSED the next week.

Dr. X stated, "No. I will not allow this. This is suicide. This is wrong. I have a patient who is much older than you. He has Alzheimer's and he loves music. His life has value because he gets up each day and listens to music. Your life has value. So, no. I will not allow this." Dr. X left the examining room and Mr. P returned home assuming Dr. X' position would have no bearing on his upcoming VSED since Dr. X was not responsible for Mr. P's Alzheimer's medical care or hospice referral.

Within half an hour, the hospice agency with which Mr. P had met, called Mr. P and stated that it was rescinding its upcoming admission. The representative explained that hospice had received a call from Dr. X, who stated, "Mr. P does not qualify for hospice. Mr. P will never qualify for hospice because he is choosing to stop eating and drinking. This is up to God, not Mr. P."

Mr. P contacted his Alzheimer's physicians and told them what had happened.[10] Surprised by Dr. X's interference and hospice's response, Mr. P's physicians began contacting other hospices so that Mr. P could commence VSED as planned. The next day, the United States went into COVID-19 lockdown and Mr. P's physicians could not find any hospices taking new patients.

After a few months of continued lockdown, Mr. P, worried that his window of competency would soon close, determined that he had no choice but to begin VSED. He consulted with his Alzheimer's physicians and commenced VSED. Mr. P's physicians were unable to find a hospice taking patients until day eight of Mr. P's VSED.

A hospice nurse came on day eight to evaluate Mr. P, who had not eaten any food nor consumed any fluids in eight days. He was bedridden and could barely speak. Mr. P's anxiety was extreme and focused on whether Dr. X or anyone else would try to stop him from completing VSED. Mr. P's lips and mouth were parched, swollen, and covered in white blisters. His hands and feet were cold and turning blue. His breathing was labored, rattled, and shallow. Given these symptoms, Mr. P clearly qualified for admission to hospice. When the hospice nurse learned that Mr. P was VSED, however, the nurse declined to admit him and left.

Hope Wechkin et al., *Clinical Guidelines for Voluntarily Stopping Eating and Drinking* (VSED), 55 J. PAIN & SYMPTOM MGMT. 625, 626 (2023) [hereinafter *Clinical Guidelines for VSED*].

[9] *See, e.g.*, ALIVE HOSPICE, HOSPICE ELIGIBILITY: A RESOURCE FOR PHYSICIANS AND HEALTH CARE PROVIDERS 4 (2021) (detailing hospice eligibility for differing conditions).

[10] *See id.*

Mr. P's doctors called another hospice agency which sent a nurse the next morning to evaluate Mr. P, who was weaker and whose breathing was more labored. Again, when the nurse learned that Mr. P was VSED, he was refused admission. Mr. P's doctors called a fourth hospice that came on the evening of day nine of Mr. P's VSED. The nurse took a medical history including Mr. P's decision to VSED. This hospice admitted Mr. P to service. On day ten, Mr. P went into terminal agitation for hours before becoming fully unconscious. He died forty hours after being admitted to hospice.

III. Part Two: Clinical Facts

A. Alzheimer's Disease

Alzheimer's disease is a progressive brain disorder that causes the brain to atrophy and memory and cognitive skills to decline.[11] It is one type of dementia that afflicts humans.[12] Other dementia diseases include Lewy Body, frontotemporal, and vascular.[13] Alzheimer's disease accounts for about 70% of dementia cases.[14]

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[11] *See What Happens to the Brain in Alzheimer's Disease?*, NAT'L INST. ON AGING (Jan. 19, 2024), https://www.nia.nih.gov/health/alzheimers-causes-and-risk-factors/what-happens-brain-alzheimers-disease [https://perma.cc/3FN8-VYR7] [hereinafter *What Happens to the Brain in Alzheimer's Disease?*]; *see also Alzheimer's Disease Fact Sheet*, NAT'L INST. ON AGING (Apr. 5, 2023), https://www.nia.nih.gov/health/alzheimers-and-dementia/alzheimers-disease-fact-sheet [https://perma.cc/CE3R-RU4U] [hereinafter *Alzheimer's Disease Fact Sheet*] (discussing Alzheimer's disease commonality). In the United States, Alzheimer's disease is one of the top ten leading causes of death. *Alzheimer's Disease Fact Sheet*, *supra*. Among individuals, symptoms typically emerge later in life. *Id.*

[12] *See Infographic: Understanding Different Types of Dementia*, NAT'L INST. ON AGING (June 5, 2022), https://www.nia.nih.gov/health/alzheimers-and-dementia/understanding-different-types-dementia [https://perma.cc/3WNN-9WWY] (describing dementia differences); *see also Stages of Alzheimer's*, ALZHEIMER'S ASS'N (2026), https://www.alz.org/alzheimers-dementia/stages [https://perma.cc/65FX-VJVG] (detailing Alzheimer's disease progression). At the early stages of Alzheimer's disease, an individual can participate in normal activities such as driving, working, and social activities, but may forget words, names, or locations. *Stages of Alzheimer's*, *supra*. At the moderate stages, symptoms vary, but a person may experience intensified signs such as forgetting important events or information, sleep pattern interruptions, and behavior changes. *Id.* At the late stages, an individual may require consistent personal care, may not be able to communicate, or have a weaker immune system. *Id.*

[13] *See Alzheimer's Disease Fact Sheet*, *supra* note 10 (analyzing Alzheimer's disease's impacts); *Dementias*, NAT'L INST. NEUROLOGICAL DISORDERS & STROKE (Mar. 13, 2026), https://www.ninds.nih.gov/health-information/disorders/dementias [https://perma.cc/H8H8-XGL8] (explaining basics of dementia). Lewy Body dementia is the second leading cause of dementia. *Dementias*, *supra*. This type of dementia affects the cortex and the substantia nigra. *Id.* Frontotemporal dementia [hereinafter *FTD*] consists of the nerve cells affecting the frontal and temporal lobe of the brain. *Id.* FTD consists of multiple syndromes: behavioral variant frontotemporal dementia, primary progressive aphasia, corticobasal degeneration, frontotemporal dementia with motor neuron disease, Pick's disease, and progressive supranuclear palsy. *Id.* Vascular dementia infects the cognitive functions of the brain. *Id.*

[14] *See Dementia vs Alzheimer's Disease: What's the Difference?*, ALZHEIMER'S ASS'N, https://www.alz.org/alzheimers-dementia/difference-between-dementia-and-alzheimer-s [https://perma.cc/4N5W-87UQ] (describing dementia and Alzheimer's differences). Dementia is classified as a more general brain disease, while Alzheimer's is a specific type of dementia. *Id.*; *see also About Dementia*, CDC: ALZHEIMER'S DISEASE & DEMENTIA (Aug. 17, 2024), https://www.cdc.gov/alzheimers-dementia/about/index.html [https://perma.cc/4SH7-34HL] (highlighting growing dementia issues).

One out of nine individuals aged sixty-five or older and one in three aged eighty-five or older have Alzheimer's disease.[15] Alzheimer's is the leading cause of death for American women and the ninth leading cause for American men.[16] In the United States, someone develops Alzheimer's every sixty-seven seconds.[17] In the years ahead, cases of dementia will increase as Boomers age and Gen X and Millennials begin to manifest Alzheimer's symptoms.[18]

The average age of Alzheimer's diagnosis is seventy-five years.[19] The average age of early onset Alzheimer's is fifty-five years.[20] Individuals with Alzheimer's disease

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[15] *See* 2025 ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 3, at 29. While Alzheimer's disease is most common in older individuals, younger adults may also be susceptible to the disease. *Id.* Between the ages of thirty and sixty-five, about 0.11% of individuals may develop early on-set dementia. *Id.*; *see also Alzheimer's Disease Frequently Asked Questions (FAQs)*, N.Y. STATE DEP'T OF HEALTH (Dec. 2024), https://www.health.ny.gov/diseases/conditions/dementia/faqs.htm [https://perma.cc/UMH3-EHAP] (analyzing racial differences between one in nine individuals). Above the age of sixty-five, around fourteen percent of Black Americans are most likely to be diagnosed with Alzheimer's disease. N.Y. STATE DEP'T OF HEALTH, *supra.* Additionally, twelve percent of Hispanic individuals and ten percent of white adults are likely to receive an Alzheimer's disease diagnosis. *Id.*

[16] *See* CDC: ALZHEIMER'S DISEASE & DEMENTIA, *supra* note 13 (comparing previous years' data). Nationally, Alzheimer's disease is the seventh leading cause of death. *Id.*; *see also* 2025 ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 3, at 31 (describing differences between men and women). Currently, 1.6 million more women have Alzheimer's disease than men. 2025 ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 3, at 31.

[17] *See Facts & Stats*, ALZHEIMER'S SAN DIEGO (2026), https://www.alzsd.org/resources/facts-stats/ [https://perma.cc/Q5W5-DY92] (projecting rises in Alzheimer's cases). It is likely that around 500,000 cases will be diagnosed in the upcoming year. *Id.*; *see also New Alzheimer's Association report finds less than half of people with Alzheimer's disease say they were told the diagnosis*, ALZHEIMER'S ASS'N (Mar. 23, 2015), https://www.alz.org/news/2015/new-alzheimer-s-association-report-finds-less-than-half-of-people-with-alzheimer-s-disease-say-they [https://perma.cc/38PR-TMJU] [hereinafter *New Alzheimer's Association*] (explaining lack of communication with diagnosis). The rate of development is expected to accelerate from sixty-seven seconds every thirty-three seconds. *New Alzheimer's Association*, *supra.*

[18] *See Early-Onset Dementia and Alzheimer's Diagnoses Spiked 373 Percent for Generation X and Millennials*, BLUECROSS BLUESHIELD (Feb. 27, 2020), https://www.bcbs.com/about-us/association-news/early-onset-dementia-and-alzheimers-diagnoses-spiked-373-percent-generation-x-and-millennials [https://perma.cc/X4X6-V5SL]; *see, e.g.*, Clare Ansberry, J. (Apr. *Mom and Dad Are in Their 80s. Their Son Is the One With Dementia.*, https://www.wsj.com/health/wellness/mom-and-dad-are-in-their-80s-their-son-is-the-one-with-dementia-25f88df2 [https://perma.cc/KAZ6-RM8S] (exemplifying early onset dementia). Between the ages of thirty and sixty-four, about 200,000 people in the United States are living with a form of dementia including Alzheimer's. Ansberry, *supra.*

[19] *See* 2025 ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 3, at 29; *see also Alzheimer's disease*, MAYO CLINIC (Mar. 3, 2026), https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/syc-20350447 [https://perma.cc/EVY6-BK5C] [hereinafter *Alzheimer's disease*] (articulating Alzheimer's symptoms). As individuals grow older, the likelihood of developing Alzheimer's disease increases. *Alzheimer's disease*, *supra.*

[20] *See Early-Onset Alzheimer's Disease*, CLEV. CLINIC (Mar. 17, 2024), https://my.clevelandclinic.org/health/diseases/9592-early-onset-alzheimers-disease [https://perma.cc/Q77P-FJ54]. Two known proteins to cause early-onset Alzheimer's disease are amyloid and tau. *Id.* "Amyloid protein sticks together in your brain cells, forming clumps called plaques. Tau proteins twist together in fiber-like strands called tangles." *Id.*; *see also Early-Onset Alzheimer's Disease*, JOHNS HOPKINS MED.,

live an average of eight to fourteen years after diagnosis, although some live as long as twenty years.[21]

Alzheimer's "is more feared… than cancer, stroke, and heart disease combined."[22] Unlike diseases that affect the physical body, Alzheimer's attacks the brain and takes a patient's memory, cognition, and ultimately, their identity.[23] Alzheimer's will, to a medical certainty, take from individuals all awareness of who they are and who they have been.[24] As the disease progresses into its last two stages, Alzheimer's reduces individuals to complete dependence on others for every aspect of daily life.[25] By stage seven, once vibrant, active, engaged persons are reduced to bedridden, diapered creatures, unaware of who they are or where they are, unable to recognize loved ones, unable to speak, unable to smile.[26] Persons live in the last two stages of Alzheimer's an average of 3.4 years.[27]

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https://www.hopkinsmedicine.org/health/conditions-and-diseases/alzheimers-disease/earlyonset-alzheimer-disease [https://perma.cc/XP9M-B3ZX] (describing early-onset dementia causes). Individuals with known family history of the disease are most at risk for early-onset Alzheimer's. JOHNS HOPKINS MED., *supra*.

[21] *See* 2025 ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 3, at 8; *2024 Alzheimer's Disease Facts and Figures*, 20 ALZHEIMER'S & DEMENTIA 3708, 3710 (2024) (portraying life after diagnosis). After diagnosis, factors that affect lifespan are the following: (i) age at diagnosis, (ii) progression of disease, and (iii) the presence of other health conditions or mixed dementia. ALZHEIMER'S & DEMENTIA, *supra*. Some individuals may require around-the-clock care as their disease escalates. *Id.*

[22] *See* MILKEN INST. *Dementia: Addressing the Stigma of America's Most Feared Diagnosis*, at 00:16 (Milken Inst., June 21, 2021), https://milkeninstitute.org/video/dementia-addressing-stigma [https://perma.cc/KTM6-CYWR] (giving dementia overview)[hereinafter Milken Inst., June 21, 2021] ; *see also* Weizhou Tang et al., 71 *Concern About Developing Alzheimer's Disease or Dementia and Intention to be Screened: An Analysis of National Survey Data*, ARCH GERONTOLOGY & GERIATRICS 43, 43 (2017) (discussing early testing controversies). Individuals are encouraged to test early for dementia. Tang et al., *supra*. The more likely someone is of developing the disease, the more likely they are of getting tested earlier. *Id.* Some worry that earlier testing can lead to emotional, time or cost detriments. *Id.*

[23] *See Alzheimer's Disease*, CLEV. CLINIC (Feb. 19, 2025), https://my.clevelandclinic.org/health/diseases/9164-alzheimers-disease [https://perma.cc/SLY7-4EPY]; *What Happens to the Brain in Alzheimer's Disease?*, *supra* note 10.

[24] *See Lost in Identity: How Alzheimer's Patients Struggle with Self-Recognition*, CAREYAYA HEALTH TECH., https://www.careyaya.org/resources/blog/lost-in-identity-how-alzheimer-s-patients-struggle-with-self-recognition#: [https://perma.cc/T75V-7EB8] (describing influence on self-perception); Emilie Reas, *Can Alzheimer's Disease Steal One's Consciousness?*, PUB. LIBR. OF SCI.: OFFICIAL PLOS BLOG (Apr. 3, 2017), https://theplosblog.plos.org/2017/04/can-alzheimers-disease-steal-ones-consciousness/#: [https://perma.cc/737G-ZKG3]. Alzheimer's is often categorized as a disorder of "impaired attention to life" because patients are unable to recall or emotionally engage with episodic memories, thereby eradicating their conscious awareness of the experience. *Reas*, *supra*.

[25] *See Stages of Alzheimer's*, *supra* note 11. In addition to complete dependency, the patient's ability to initiate engagement with loved ones is often significantly reduced. *Id.*

[26] *See id.* (highlighting stages of disease progression); *Clinical Stages of Alzheimer's*, FISHER CTR. FOR ALZHEIMER'S RSCH. FOUND., https://www.alzinfo.org/understand-alzheimers/clinical-stages-of-alzheimers/ [https://perma.cc/XJ4V-5WV2]. The final stage results in the patient's inability to naturally hold their own head up. *Clinical Stages of Alzheimer's*, *supra*; *see also Care in the Last Stages of Alzheimer's Disease*, NAT'L INST. ON AGING, https://www.nia.nih.gov/health/alzheimers-caregiving/care-last-stages-alzheimers-disease [https://perma.cc/8U4M-GSBK] (explaining final stages of Alzheimer's disease).

[27] *See* Barry Reisberg & Emile H. Franssen, *Clinical Stages of Alzheimer's Disease*, ENCYCLOPEDIA VISUAL MED. SERIES: ATLAS ALZHEIMER'S DISEASE, 17-18 (Mony J. de Leon ed., 1999); *see also* 2025

Experts describe Alzheimer's disease as a tsunami hurling our way.[28] Tsunami is an apt term for dementia diseases.[29] Like a tsunami that builds in the ocean offshore, hidden from view until just before it gathers strength to devastate all in its path, dementia begins in the body long before it explodes full force decades later. [30]

B. Voluntary Stopping Eating and Drinking

VSED is "a deliberate, voluntary, self-initiated action to hasten death by a patient with decision-making capacity who is suffering from an irreversible illness or prolonged dying that the person finds intolerable."[31] Although VSED is a lawful end-of-life option, "most people don't know about it or fully understand it."[32] Palliative care experts note that this is beginning to change as the population ages, serious chronic and terminal illnesses become more prevalent, more individuals seek control over the circumstances of their death, and VSED gains recognition as a viable, legal, and peaceful end-of-life option.[33]

ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 3, at 10 (describing disease continuum and relevant statistics).

[28] *See* Nobel Chenggong Zong et al., *Addressing Healthy Aging: Time to Stop a Tsunami of Rising Alzheimer's Disease*, 16 AGING & DISEASE 3229, 3229 (2025). Because the population at risk of Alzheimer's is expected to increase significantly in the next few decades, innovations in prevention, diagnostics, and therapeutics are necessary to "flatten the curve." *Id.* at 3231; *see also* Chris Killian, *The Dementia Tsunami is Here: A Wake-Up Call for At-Home Care*, HOME CARE INNOVATION F. (July 10, 2025), https://info.homecareinnovationforum.com/the-dementia-tsunami-is-here-a-wake-up-call-for-at-home-care [https://perma.cc/5FYD-QAJN] (highlighting importance of specialized care models).

[29] *See* Killian, *supra* note 27 (explaining prevalence of dementia crisis).

[30] *See* ALZHEIMER'S ASS'N, GENERATION ALZHEIMER'S: THE DEFINING DISEASE OF THE BABY BOOMERS 6 (2011); *see also* Killian, *supra* note 27(describing limitations of therapeutic intervention). Existing drugs are only effective if the disease is caught early, leaving little hope for adults already affected. Killian, *supra* note 27.

[31] *See* Wechkin et al., supra note 7, at e626. VSED is dependent on the patient's sufficient decisional capacity, rendering it clinically distinct from those ordered under advanced directive or comfort feeding approaches. *Id.* at Lete626.Let's

[32] *See* VOLUNTARILY STOPPING EATING AND DRINKING: A COMPASSIONATE, WIDELY AVAILABLE OPTION FOR HASTENING DEATH (Timothy E. Quill et al. eds., Oxford Univ. Press 2021) [hereinafter *VSED TREATISE*]; *see also* Sabrina Stängle, Wilfried Schnepp, & André Fringer, *The Need to Distinguish Between Different Forms of Oral Nutrition Refusal & Different Forms of Voluntary Stopping of Eating & Drinking*, 13 PALLIATIVE CARE & SOC. PRAC., Oct. 2019, at 1 (distinguishing various forms of nutrition refusal).

[33] *See* David A. Gruenewald, *Voluntarily Stopping Eating and Drinking: A Practical Approach for Long-Term Care Facilities*, 21 J. PALLIAT. MED. 1214, 1215-18 (2018) [hereinafter *Gruenewald, Long-Term Care Facilities*] (noting change in trend of VSED recognition and availability). The "growing population of older adults, the high prevalence of severe chronic degenerative and lethal diseases" has led to the increase in the desire for people "to control the circumstances of their dying." *Id.* at 1218. VSED offers several advantages as an end-of-life option, particularly for patients seeking autonomy and control. *Id.* at 1215. It allows individuals to hasten death on their own terms while still preserving the opportunity to reconsider their decision, spend meaningful time with loved ones, and engage in reflection and closure during the dying process. *Id.*

The VSED process typically lasts less than fourteen days and, with adequate medical and hospice support, is reported to be peaceful and pain free.[34] The length of one's VSED depends on whether a person consumes any fluid, as even tiny sips of water can prolong the process by weeks, even months.[35] The physiological process of fasting brings a natural anesthetic and pain relief for individuals.[36] However, while the sensation of hunger generally abates within the first twenty-four through forty-eight hours, the discomfort from dehydration continues throughout the process and requires treatment for dry mouth pain as well as for the anxiety and delirium dehydration may bring.[37]

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[34] *See* Christina Mensger et al., *Voluntarily Stopping Eating and Drinking (VSED): A Systematic Mixed-Methods Review Focusing on the Carers' Experiences*, 150 HEALTH POLICY 105174, 105176-77 (2024) (reporting on duration and general experience of VSED). As described in a 2024 systematic review of literature on VSED:

> VSED [is] considered a dignified death. Relatives and health care professionals who accompanied a person during VSED described it as a beautiful and amazing experience and the dying process as calm, peaceful and not stressful for the patient and that the process mostly met the patients' expectations. Moreover, patients were described as happy and relieved to have this option. The situation for patients and relatives during the course of the VSED was described as enriching and satisfying for both. There was time to say goodbye, settle affairs, and spend time together, which the relatives also saw as a gift to themselves. Family cohesion increased during that time, which was experienced as helpful and supportive. Finally, most health care professionals (73-75%) could also imagine VSED for themselves, as could relatives who had accompanied a loved one during VSED.

Id.; *see also* Judith Schwarz, *Hospice Care for Patients Who Choose to Hasten Death by Voluntarily Stopping Eating and Drinking*, J. HOSP. PALLIATIVE NURSING 126, 129 (2014) (discussing peacefulness and duration of VSED); VSED TREATISE, *supra* note 31, at 34-59 (emphasizing peaceful nature of VSED).

[35] *See* Jane Lowers, Sean Hughes, & Nancy J. Preston, *Overview of Voluntarily Stopping Eating and Drinking to Hasten Death*, 10 ANNALS PALLIATIVE MED. 3611, 3612 (2021) (discussing effects of eating or drinking during VSED). *See id.* at 3612 (outlining effects of fluid intake on VSED process). Even minimal fluid intake during VSED can significantly delay the dying process, as even small sips of water or ice chips may slow dehydration and extend the progression toward death. *Id.* Because dehydration is the primary physiological mechanism driving death in VSED, continued intake of even small quantities of fluid can prolong the dying process well beyond its expected course. *Id.*; *see also* VSED TREATISE, *supra* note 31, at 45-47 (reiterating how VSED gets prolonged by hydration).

[36] *See* Vicki D. Lachman, *Voluntary Stopping Eating and Drinking: An Ethical Alternative to Physician-Assisted Suicide*, 24 MEDSURG NURS. 56, 58 (2015) (discussing pain-relieving effects of VSED). The physiological effects of dehydration during VSED can produce analgesia, a medical term for pain relief without loss of consciousness, as metabolic imbalances in the body reduce pain perception. *Id.* Additionally, increased ketone production and endogenous opioid release may create anesthetic-like and pain-relieving effects, contributing to a more comfortable dying process. *Id.*

[37] *See* Lowers, Hughes, & Preston, *supra* note 34, at 3612 (examining process of loss of hunger). Although patients may initially anticipate hunger, reports indicate that individuals rarely experience significant or intolerable hunger during VSED as the body transitions to fat metabolism through ketosis. *Id.* As this metabolic shift occurs early in the process, hunger is generally not a prominent or persistent symptom compared to other effects such as thirst. *Id.*; *see also* Brian Donohue, *Choosing to Halt Nourishment: An End-of-Life* Decision, UW Medicine: Newsroom (Jan. 10, 2023), https://newsroom.uw.edu/blog/choosing-halt-nourishment-end-life-decision/

Patients who undergo VSED—along with the nurses, social workers, and family members who support them—describe VSED as a meaningful experience of reminiscing, sharing memories, and saying goodbyes.[38] A study in Oregon, where physician assisted dying is legally available, nearly twice as many hospice patients chose VSED over physician assisted dying.[39] A survey of Oregon hospice nurses and social workers shows strong support for VSED as an end-of-life option, with most (75%) supporting offering VSED to patients experiencing physical, psychological, or spiritual suffering; 95.4% willing to continuing to provide care to VSED patients; and 70.7% saying they would consider VSED for themselves.[40]

VSED is the only realistic, lawful end-of-life option for individuals with dementia who want to avoid dementia's last stages.[41] End-of-life options available to those with diseases that afflict the body, not the mind (such as cancer, heart disease, and the like), are not available to those with dementia. Physician Aid in Dying (PAD), also called Medical Aid in Dying (hereinafter MAID) or Dying with Dignity (hereinafter DWD), provide end-of-life options in thirteen states and the District of Columbia.[42] With these end-of-life options, a physician prescribes a lethal medication

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[https://perma.cc/J4H2-3R68] (stating hunger pains typically diminish within days); Schwarz, *supra* note 33, at 127 (emphasizing experience of dry mouth and dehydration). The discomfort associated with dehydration during VSED persists throughout the dying process and requires ongoing management through supportive care. *Id.* Patients commonly experience dry mouth and thirst, which necessitate continuous oral care and symptom relief to maintain comfort. *Id.* Accordingly, individuals undergoing VSED require continuous physical and emotional support throughout the process to address evolving symptoms and distress associated with dehydration. *Id.*; Lachman, *supra* note 35, at 58 (listing symptoms of VSED including lethargy and confusion). Dehydration produces cognitive and physiological symptoms, including confusion and other distressing effects, that must be actively managed to ensure patient comfort during the dying process. Lachman, *supra* note 35, at 58.

[38] *See Gruenewald, Long-Term Care Facilities*, *supra* note 32, at 1215 (discussing benefits of ending life with VSED). Patients, as well as caregivers and healthcare providers, have described VSED as facilitating a meaningful end-of-life experience that allows for intentional emotional closure. *Id.* This process provides patients and their families with opportunities to engage in reflection, share stories, and say goodbyes, reinforcing the relational and dignitary aspects of dying. *Id.*

[39] *See* Linda Ganzini et al., *Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death*, 349 NEW ENG. J. MED. 359, 363 (2003) (reporting VSED deaths at nearly double rate of PAD in Oregon hospice settings). Hospice nurses in Oregon reported that deaths following voluntary refusal of food and fluids occurred at nearly twice the rate of deaths from physician-assisted suicide during the same period. *Id.* at 363. This comparison reflects contemporaneous hospice experience after legalization of PAD, indicating that patients still more frequently chose VSED despite the availability of PAD. *Id.* The study thus suggests that, even in a jurisdiction permitting physician-assisted dying, VSED functions as a commonly utilized alternative means of hastening death in hospice care. *Id.* Unlike physician-assisted suicide, VSED remains legally available to competent patients nationwide and does not require physician participation, expanding access to end-of-life autonomy. *Id.*

[40] *See* Theresa A. Harvath et al., *Voluntary Refusal of Food and Fluids: Attitudes of Oregon Hospice Nurses and Social Workers*, 10 INT'L J. PALLIATIVE NURSING 236, 236 (2004) (reporting data on nurses and social workers' opinions towards VSED).

[41] *See* Lachman, *supra* note 35, at 57 (noting VSED's legality in all fifty states); *see also* Schwarz, *supra* note 33, at 128 (acknowledging most legal scholars and palliative care clinicians recognize legality of VSED). Terminally ill patients with advanced disease often desire death to end the pain. Schwarz, *supra* note 33. Most palliative clinicians agree that patients with immense suffering should be informed of all legal options such as withdrawing from life-sustaining interventions, VSED, and sedation into unconsciousness. *Id.*

[42] *See States Where Medical Aid in Dying is Authorized*, COMPASSION & CHOICES, https://compassionandchoices.org/states-where-medical-aid-in-dying-is-authorized. The jurisdictions that have PAD are: California (2015), District of Columbia (2017), Colorado (2016),

for qualifying patients, which patients administer to themselves to bring about their death. These options are not available to Alzheimer's patients because these statutes require that a person be cognitively competent to qualify for PAD (or MAID, or DWD).[43] They also require that individuals must be within six months of death to qualify.[44] No one with an advanced enough state of Alzheimer's to be within six months of dying will still be cognitively competent.[45] Thus, no one with Alzheimer's disease can qualify under PAD, MAID, or DWD statutes.[46]

Travel to another country where forms of assisted dying are available to non-residents, such as the Netherlands, Belgium, Switzerland, or Luxembourg, is unrealistic for most individuals with dementia because of the travel required, coupled with the required competency assessments and the unpredictability of the loss of competence.[47] As one U.K. psychiatrist who has conducted evaluations for hundreds

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Delaware (2025), Hawaii (2019), Illinois (2025), Maine (2019), Montana (2009), New Jersey (2019), New Mexico (2012), New York (2026), Oregon (1990), Vermont (2013), Washington (2009). *Id.* PAD statutes include a number of requirements such as: the person seeking PAD is a capable adult who is determined by two physicians to have a terminal disease; has voluntarily made a written request for medication for the purpose of "ending his or her life in a humane and dignified manner"; complied with the time deadlines; undergone assessments by physicians of disease status as well as of any psychiatric or psychological disorders that may be causing impaired judgment; submitted to medication record review and documentation. *Id.* These statutes have a number of reporting requirements, and address the effect of PAD on wills, contracts; statutes, and insurance or annuity provisions. *Id.* PAD statutes provide immunity from criminal, civil, and professional disciplinary action for participating in good faith with the PAD requirements. *Id.* S*ee, e.g.* ORS § 127.885 (2026).

[43] *See, e.g.*, Emily A. Largent et al., W*hen People Facing Dementia Choose to Hasten Death: The Landscape of Current Ethical, Legal, Medical, and Social Considerations in the United States,* HASTINGS CENTER REPORT 54, no. S1 at S12 (2024), 10.1002/hast.1550 [hereinafter *The Landscape,* HASTINGS CENTER REPORT].

> "Medical Aid in Dying (MAiD) and Physician Assisted Dying 'involves the prescription of a lethal dose of medication to a capacitated, terminally ill adult with a prognosis of six months or less who may self-administer this medication to hasten death. People with a primary diagnosis of dementia who meet the self-administration requirement are unlikely to simultaneously meet the capacity requirement and the six-month prognosis requirement; because all three requirements must be met, people with a primary diagnosis of dementia are effectively excluded from MAID.'"

Id. Nor is traveling to another country such as the Netherlands, Switzerland, or Luxembourg, where a form of assisted dying is available to non-residents, realistic for individuals with Alzheimer's because of the timing of the various required competency assessments and travel. *Id.*; *see also* COLIN BREWER, O, LET ME NOT GET ALZHEIMER'S SWEET HEAVEN! 222 (Skyscraper Publications 2019). As one U.K. psychiatrist who has conducted evaluations for hundreds of patients who seek to qualify under these statutes explains: "This web of assessments, deadlines, and records is insurmountable for most patients with Alzheimer's disease because of the unpredictable nature of their disease and their inability to retain competency as their disease progresses." *Id.*

[44] *See The Landscape,* HASTINGS CENTER REPORT, *supra* note 42 at S12.

[45] *See id.*

[46] *See id.*

[47] *See* J. Pereira, *Legalizing Euthanasia or Assisted Suicide: The Illusion of Safeguards and Controls*, 18 CURRENT ONCOLOGY 38, 38 (2011) (explaining extension of euthanasia and PAD eligibility in numerous countries). The Netherlands and Luxembourg legalized both euthanasia and PAD in 2009 and 2001, respectively. *Id.* Belgium also legalized euthanasia in 2002. *Id.* Although Switzerland has not formally legalized assisted suicide, it has decriminalized suicide, but

> of patients seeking to qualify under these statutes, explains, the competency assessments, deadlines and records are not feasible for many Alzheimer's patients because of the unpredictability associated with the disease and the diminishment in competency throughout disease progression.[48]

A number of advantages exist for choosing VSED over other end-of-life options.[49] Because of the nature of VSED and the clinical guidelines that apply to it, VSED carries little risk of impulsive or hasty decisions, or decisions made when one is suffering from depression or other mental illness, or from any illness for which there is treatment or cure.[50] Because there is no lethal medication involved, VSED is often a preferable option for patients with ethical, religious, or other personal objections to physician assisted dying.[51] Because there is no third party involved in the act of VSED, VSED is not euthanasia (a practice outlawed in the U.S. and many countries), in which a third party causes the death of another person.[52] There is no third party involved in the

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euthanasia remains illegal. *Id.* In Belgium, legislators announced their intent to include people with dementia or Alzheimer disease in euthanasia laws. *Id.* at 41; *Id.* at 39 (highlighting various safeguards to euthanasia and PAD laws, including competence and consent). All countries permitting euthanasia or PAD require it to be voluntary, well-considered, informed, and persistent over time. *Id.* The patient must provide an explicit, written consent statement while they are competent. *Id.*

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[48] *See* COLIN BREWER, O, LET ME NOT GET ALZHEIMER'S SWEET HEAVEN! 222 (2019); *see also* AMY BLOOM, IN LOVE: A MEMOIR OF LOVE AND LOSS (2022) (discussing difficulty of certification process for patients with Alzheimer's disease). Bloom tells her husband's experience seeking to obtain physician assisted death in Switzerland before his Alzheimer's advanced too far. BLOOM, *supra*.

[49] *See Gruenewald, Long-Term Care Facilities*, *supra* note 37, at 1216 (highlighting reasons for some patients opting for VSED). Because VSED does not require an imminently lethal diagnosis and is more widely accessible than PAD, many patients find it advantageous. *Gruenewald, Long-Term Care Facilities*, *supra* note 37, at 1216; Lachman, *supra* note 35, at 57 (comparing end-of-life treatment options). Furthermore, VSED provides patients with the opportunity to change their mind during the process. Lachman, *supra* note 35, at 57.

[50] *See Clinical Guidelines for VSED*, *supra* note 7, at 626. The clinical guidelines clearly state that a comprehensive evaluation of a patient's reasoning for seeking VSED is important in identifying potential mental health issues to be addressed through adequate therapy and support. *Id.* Further, that a patient's "decision-making capacity" is a necessary element for them to begin VSED, when that capacity is unclear, ethical concerns will arise. *Id.* For instance, when mental health disorders affect ones decision-making capacity, clinicians are required to verify that the patient has full understanding of their diagnosis, and "the risks, benefits, and alternatives to VSED." *Id.*

[51] *See* Ganzini et al., *supra* note 38, at 364; *see, e.g.*, *Clinical Guidelines for VSED*, *supra* note 7, at 626 (providing guidelines on provision of VSED). The Clinical Guidelines for VSED provide the following guidance:

> Comprehensive evaluation of the patient's reason for seeking VSED is especially important in these situations, as this may identify aspects of suffering, including mental health and spiritual issues that can be addressed and ameliorated. Patients may benefit from appropriate therapy and support and should be encouraged to explore these options before pursuing VSED.

Clinical Guidelines for VSED, *supra* note 7, at 626; Harvath et al., *supra* note 39, at 539 (analyzing nurse and social worker experiences with forms of assisted-death); VSED TREATISE, *supra* note 31, at 51 (discussing legal history of VSED).

[52] *See* JOHN KEOWN, EUTHANASIA, ETHICS, AND PUBLIC POLICY (Cambridge Univ. Press 2018).

act of VSED, only the patient is an active participant.[53] Because there is no fetus at issue, VSED does not raise issues at the heart of the abortion debate. Similarly, VSED does not present the issues underlying the vaccination debate as VSED impacts only the life and health of the person choosing VSED, not the community's health.

The legality of VSED is clear. As Professor Thaddeus Pope, the foremost expert on the law surrounding VSED, writes: "A patient's right to VSED is settled law."[54] Every court in the United States and elsewhere that has considered the legality of VSED has ruled that VSED is legal.[55] As Professor Pope states: "Perhaps the best evidence of VSED's recognition and acceptance is its widespread practice."[56]

IV. Part Three: Relevant Ethical Principles

A. Normative Ethics: Immanuel Kant and John Stuart Mill

Ethics, the study of what is right and wrong in behavior, is governed by a variety of principles that are relevant to end-of-life decisions.[57] One such principle, autonomy of the individual, has been articulated by Immanual Kant and John Stuart Mill.[58] As Kant stated: "All persons have intrinsic and unconditional worth, and therefore, should have the power to make relational decisions and moral choices, and

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[53] *See Clinical Guidelines for VSED*, *supra* note 7, at 626. VSED is defined as a deliberate and self-initiated action by the patient. *Id.* at 626.

[54] *See* VSED Treatise, *supra* note 31, at 80-105. In this treatise and elsewhere, Pope provides a comprehensive overview of the legal history of VSED. *Id.*; *see also* Timothy E. Quill et al., *Voluntarily Stopping Eating and Drinking Among Patients with Serious Advanced Illness—Clinical, Ethical, and Legal Aspects*, 178 JAMA Internal Med. 123, (2018) [hereinafter *Clinical, Ethical, and Legal Aspects VSEP*] (discussing clinician participation in assessing and managing VSED facilitation); Thaddeus Mason Pope, *Voluntarily Stopping Eating and Drinking (VSED) to Hasten Death: May Clinicians Legally Support Patients to VSED?*, BMC Med., Oct. 2017, at 1, 2 (comparing and analyzing law's consideration toward two end-of-life options).

[55] *See* VSED Treatise, *supra* note 31, at 85-110. *See generally* Sabrina Stängle et al., *Voluntary Stopping of Eating and Drinking in Swiss Outpatient Care*, 34 GeroPsych 73, 73 (2021) (evaluating nurses attitudes towards VSED in outpatient care); Takuya Shinjo et al., *Japanese Physicians' Experiences of Terminally Ill Patients Voluntarily Stopping Eating and Drinking: A National Survey*, 9 BMJ Supportive & Palliative Care 143, 143 (2019) (investigating experience of home hospice physicians caring to patients undergoing VSED in Japan); Nataša Ivanović, Daniel Büche, & André Fringer, *Voluntary Stopping of Eating and Drinking at the End of Life - A 'Systematic Search and Review' Giving Insight into an Option of Hastening Death in Capacitated Adults at the End of Life*, BMC Palliative Care, Jan. 2014, at 1, 2 (reviewing literature concerned with VSED options to exit-life).

[56] *See* VSED Treatise, *supra* note 31, at 87.

[57] *See Moral*, Merriam-Webster, https://www.merriam-webster.com/dictionary/moral [https://perma.cc/9FCV-NHFE].

[58] *See* Shelia Mclean, *Autonomy, Consent and the Law*, 11 Clinical Med. 94, 94 (2011). Initially, the word "autonomy" was traditionally applied to Greek cities. *Id.* It was not until Immanuel Kent who is credited to modernizing autonomy. *Id.* Kent was concerned with "rational self-governance" and individuals undertaking decisions of what they desire. *Id.* John Stuart Mill approaches autonomy in a different view than Kent. *Id.* Mill's approach defines autonomy as individuals as "masters" of their own fate. *Id.* He notes that individuals should have the decision to choose what they want to do and for any reason on the condition that it does not harm other people. *Id.*

each should be allowed to exercise his or her capacity for self-determination."[59] John Stuart Mill provides the following rationale for honoring the autonomy of each person:

> No one else can know what is truly important to another… neither one person, nor any number of persons, is warranted in saying to another human creature of ripe years, that he shall not do with his life for his own benefit what he chooses to do with it. He is the person most interested in his own wellbeing. The interest which any other person, except in cases of strong personal attachment, can have in it, is trifling, compared with that which himself has.[60]

Related to this principle of personal autonomy is the ethical obligation of each person to "respect the personal autonomy of other individuals."[61] According to Kant: "The rule of right behavior is always to act in a manner in which we should wish all other people to act."[62] Treating others with respect is fundamental to ethical behavior because, according to Kant:

> Moral behavior is behavior towards other men… rational beings have a value for themselves, which cannot be measured in terms of the relative value they may have for other people. Recognition in others of the same absolute worth as each one of us finds in himself is the basis of moral behavior.[63]

Both of these ethical principles—autonomy of the individual and the respect for the autonomy of other persons—are limited by a third ethical principle: A person's conduct shall not harm others.[64] Taken together, these three principles provide the normative ethics framework for examining the question whether competent adults, including those with Alzheimer's disease who retain cognitive capacity, have the right to

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[59] *See* Paul Guyer, *Kant on the Theory and Practice of Autonomy*, 20 Soc. Phil. Pol'y 70, 70 (2003); Basil Varkey, *Principles of Clinical Ethics and their Application to Practice*, 30 Med. Principles & Prac. 17, 19 (2020). This idea of an individual having the free will to decision was affirmed in 1914 when Justice Cardozo provided this point in his opinion in *Schloendorff v. Society of New York Hospital*. Varkey, *supra*. *See generally Scholendorff* v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914) (declaring individuals have right to decide what to do with their body). Justice Cardozo provides an example that if a surgeon performs an operation without the patient's consent, the patient could recover damages reasoning that he did not make the decision. *Id.* at 130.

[60] *See* John Stuart Mill, On Liberty 143 (Richard A. Wasserstrom, ed., Wadsworth Pub. Co. 1971) (1859) [hereinafter On Liberty].

[61] *See* Varkey, *supra* note 58, at 19 (discussing Kant and Mill's rationales on autonomy); *see also* Jukka Varelius, *The Value of Autonomy in Medical Ethics*, 9 Med. Health Care Phil. 377, 379-380 (2006) (discussing importance of individuals making own decisions); Kim Treiger-Bar-Am, *In Defense of Autonomy: An Ethic of Care*, N.Y.U. J. L. Liberty 548, 596 (2008) (arguing communication of two individuals creates ethical obligation).

[62] *See* Benjamin Apthorp Gould Fuller, A History of Philosophy 246 (Holt, Rinehart, & Winston, 3rd ed. 1955); Philip A. Pecorino, Introduction to Philosophy: An Online Textbook ch. 8 (2000) (ebook). Kant defined this maxim as "Categorical Imperative." Pecorino, *supra*. One criticism of this maxim is that it would not apply to those who are not human, or humans who do not think rationally. *Id.*

[63] *See* Fuller, *supra* note 61, at 248-249 (discussing Kant's reasoning on ethical behavior).

[64] *See* Immanuel Kant, Practical Philosophy (Mary J. Gregor ed., Cambridge U. Press 1996); Neil Duxbury, *Golden Rule Reasoning, Moral Judgment, and Law*, 84 Notre Dame L. Rev. 1529, 1556 (2009); Carl Cranor, *Toward a Theory of Respect for Persons*, 12 Am. Phil. QuarterQ.Quarter 309, 319 (1975).

determine when and how they wish to die, as well as the related question regarding the ethical obligations of health care professionals and society as a whole.[65]

B. What Ethicists Say About VSED

The first academic publications addressing ethical issues raised by VSED began to appear in the 1990s.[66] Since then, there has been an explosion of academic writings on VSED.[67] Authors of these publications come from diverse professional backgrounds and specialties, including medicine, ethics, philosophy, law, theology, and health care policy.[68] Many authors have training in multiple disciplines.[69] Throughout these works, authors cite to each other and discuss views, agree and disagree with, incorporate, refute,

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[65] *See generally* Cynthia A. Miller & Thuan D. Ong, *To Feed or Not to Feed? A Case Report & Ethical Analysis of Withholding Food and Drink in a Patient with Advanced Dementia*, 50 J. PAIN AND SYMPTOM MGMT. 887, 887 (2015) (discussing ethical obligations of medical professionals with those individuals seeking VSED).

[66] *See* Ivanović, Büche, & Fringer, *supra* note 54, at 2. VSED is considered an option to individuals who want to "preserve autonomy, to retain control, and to hasten death." *Id.* It is noted that VSED has not been examined in the last two decades which may be due to several aspects. *Id.* One aspect is that some healthcare professionals believe that stopping food intake and fluids may lead to the patient suffering more. *Id.* Another aspect is that food intake is viewed as "a symbol of social participation." *Id.* Family members would view VSED as denying their family member their needs, both physically and socially. *Id.*

[67] *See id.* at 2 (discussing historical development of hospice and palliative care practices). As the authors note, ". . . over the past 20 years voluntary stopping of eating and drinking (VSED) at the end of life has been discussed as one possibility among several to preserve autonomy, to retain control, and to hasten death without infringing the fundamental ethical principles of Western society." *Id. See generally* Scott W. Howe, *Suicide's Shadow: The Evolution of a Ghost Crime*, 90 MO. L. REV. 325, 336 (2025) (discussing VSED's exemption status to law's anti-suicide framework).

[68] *See* Lachman, *supra* note 35, at 56-57 (describing difference between voluntary stopping eating and drinking and physician-assisted suicide). Physician-assisted suicide is the killing of oneself by ingesting a lethal medication that has been prescribed by a physician. *Id.* Voluntary stopping of eating and drinking allows individuals to deliberately quicken death when other optimal palliative care options cannot relieve intolerable suffering or prolonged dying. *Id.*; *see also* Press Release, Hastings Ctr. for Bioethics, Exploring a Legal and Ethical Gray Area for People with Dementia, https://www.thehastingscenter.org/for-media/press-releases/press-release-exploring-a-legal-and-ethical-gray-area-for-people-with-dementia/ [hereinafter Exploring a Legal and Ethical Gray Area] (describing multiple commentaries on VSED for dementia patients).

> The commentaries are written by Ross Fewing, director of ethics at St. Joseph Medical Center in the PeaceHealth System in the Pacific Northwest; Timothy W. Kirk, an assistant professor of philosophy at City University of New York, York College; and Alan Meisel, the Dickie, McCamey and Chilcote Professor of Bioethics and professor of law at the University of Pittsburgh Schools of Medicine and Law.

Exploring a Legal and Ethical Gray Area*, supra.*

[69] *See* Exploring a Legal and Ethical Gray Area, *supra* note 67 (listing VSED commentary authors). Alan Meisel is both a professor of bioethics and a professor of law at the University of Pittsburg School of Medicine and the University of Pittsburg School of Law, respectively. *Id.*; *see also Alan Meisel Professor Emeritus of Law*, UNIV. PITT. SCH. L., https://www.law.pitt.edu/people/alan-meisel [https://perma.cc/JP6D-9PEQ] (describing Alan Meisel's academic and professional history). "Alan Meisel, a leading national and international authority on end-of-life decision making and informed consent to medical treatment, is the founder of the University of Pittsburgh's Center for Bioethics and Health Law and the Law School's Health Law Certificate Program." *Alan Meisel Professor Emeritus of Law, supra.*

and add to each other's views.[70] It is a rich dialogue that reflects a collaborative evolution of thought on the ethics of VSED.

The early publications on VSED reflect this evolution, for there was not, early on, even a consensus on proper terminology. Terms such as "cessation of food and fluid," "fasting from food and fluid," and "self-starvation"[71] eventually culminated in "voluntary stopping eating and drinking. There was also, in the early works, misunderstandings of facts about VSED, misstatements about clinicians' ethical obligations regarding VSED, and erroneous conflation of VSED with other end-of-life options such as sedation to termination, MAID, euthanasia, and suicide.[72] Authors of

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[70] *See* Exploring a Legal and Ethical Gray Area, *supra* note 67 (exploring relations between VSED commentary authors). *See generally* Sara Valentine, *Voluntary Stopping Eating and Drinking as a Viable End-of-Life Option in Ohio*, 47 CAP. U. L. REV. 817, 817 (2019) (discussing benefits of VSED and viability of it in Ohio). In this article, Sara Valentine cites multiple authors writing about physician-assisted suicide and VSED, as well as the Ohio Revised Code in the Modified Uniform Rights of the Terminally Ill Act, highlighting that patients have the right to refuse medical treatment. Sara Valentine argues that Ohio's code should be expanded to include VSED as a viable end-of-life option. *Id.* at 835.

[71] *See* Andrew McGee & Franklin G. Miller, *Advice and Care for Patients Who Die by Voluntary Stopping Eating and Drinking is Not Assisted Suicide*, BMC MED. Dec. 2017, at 1, 2 (arguing distinction between VSED, physician-assisted suicide, and hospice patients losing interest in eating). "VSED is distinct from the common tendency of terminally ill patients to lose interest in eating near the end of life. VSED is a form of suicide because there is unquestionably an intention to bring about one's own death." *Id.* at 2. "VSED represents an alternative way of ending one's life compared to that provided by physician-assisted suicide (PAS) in the form of ingesting prescribed lethal medication." *Id.*

[72] *See* TADEUSZ PACHOLCZK, NAT'L CATH. BIOETHICS CTR., COLUMN, WHAT IS VSED AND WHY SHOULD IT MATTER TO US? 1 (2015), https://static1.squarespace.com/static/5e3ada1a6a2e8d6a131d1dcd/t/5f28423d4c4b8c31e7467337/ [https://perma.cc/Y4T4-F82R]. "We have a moral duty to preserve and protect our life, and to use ordinary means of doing so. Suicide, even by starvation and dehydration, is still suicide and is never morally acceptable." *Id.*; *see, e.g.* THE UNIVERSITY OF CHICAGO MACLEAN CTR. FOR CLINICAL MED. ETHICS, *Daniel Sulmasy - Voluntarily Stopping Eating and Drinking: Separating the Wheat from the Chaff*, at 34:50 (YouTube, Oct. 30, 2014), https://www.youtube.com/watch?v=knxGtBmnADI [https://perma.cc/SL32-54Z5] (discussing moral opposition to patient VSED request); *see also* Wechkin et al., *supra* note 7, at 627 (discussing ethical considerations of VSED).

> While it is beyond the scope of these guidelines to address all of the arguments favoring and opposing clinician support of patients pursuing VSED, consultation from specialists in psychiatry, palliative medicine, and/ or clinical ethics should be strongly considered when there is ambiguity pertaining to the patient's mental health, DMC, and/or the clinician's role in VSED.

Wechkin et al., *supra* note 7, at 627. When considering the ethical implications of VSED, it is important to note that the suffering one experiences before choosing VSED is extraordinary and often one that is unmanageable through optimal palliative intervention or suffering from a terminal and irreversible illness that the patient deems unacceptable. *Id.* Decision making capacity is required for a patient to begin VSED and a comprehensive evaluation of the patient's reasonings for wanting to start VSED is necessary. *Id.* This assessment by a physician helps to understand the mental, physical, and emotional suffering a patient is going through to consider VSED and may be presented alternate options to VSED to ensure that VSED is what they desire. *Id.*; Bryan Murray, *Informed Consent: What Must a Physician Disclose to a Patient?*, 14 AMA J. ETHICS 563, 565 (2012) (discussing physician disclosure ethical obligations). "If, for example, a patient has become so emotionally distraught that he or she would become incapable of making a rational decision, courts generally do not require disclosure." Murray, *supra.* Physicians, however,

early VSED publications expressed legitimate ethical concerns about VSED, such as lack of adequate protocols for assessing patient competency and voluntariness.[73] Development of clinical best practices and *Clinical Guidelines on VSED* since these articles were published have now addressed these concerns.[74]

In short, the ongoing dialogue, evolving views, and development of best practices and clinical guidelines have produced a clear consensus: VSED is an ethical and moral choice when clinicians follow the safeguards, protocols, and assessments outlined in the *Clinical Guidelines for VSED*.[75] The next section discusses how and why these views evolved.

C. Reasons Why Ethicists Conclude that VSED Is Ethical

There are two basic reasons ethicists give for concluding that VSED is an ethical end-of-life option.[76] The first, noted above, is the presence of the safeguards that help ensure that VSED is used ethically.[77] The second reason returns to normative

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have an obligation to reveal enough information for the patient to make an informed decision. *Id.*; Lynn A. Jansen, *Voluntary Stopping of Eating and Drinking (VSED), Physician-Assisted Suicide (PAS), or Neither in the Last Stage of Life? PAS: No; VSED: It Depends*, 13 CTR. FOR ETHICS HEALTH CARE 410, 410 (2015) (discussing ethics of VSED). "Physicians, it is often said, should educate patients about this treatment option, recommend it as a response to end-of-life suffering, and provide support and system management throughout the process, including palliative sedation." Jansen, *supra*, at 410.

[73] *See id.* at 411 (explaining moral issues of VSED). As the author notes, ". . . in reality, VSED raises challenging moral questions about the permissibility of physician collaboration in patient decisions to end their lives as a means to ending their suffering." *Id.*

[74] *See* Wechkin et al., *supra* note 7, at 626 (discussing ethics of VSED). "The ethical questions raised by supporting a patient with a longer prognosis are not the focus of these clinical guidelines; however, clinicians should be aware that ethical concerns associated with providing clinical support for VSED generally increase with patients whose natural life expectancy is greater." *Id.* Ethical issues may arise with patients and their families after VSED has already begun, such as the patient's decision-making ability declining as the patient enters the late stages of VSED. *Id.* at 627. Patients are encouraged to discuss and document their intention to decline nutrition and hydration after VSED has begun, including after they lose their ability to fully understand and articulate their choices and decisions. *Id.*

[75] *See* Valentine, *supra* note 69, at 831 (describing benefit of VSED). "VSED gives patients the possibility of a good death, with dignity, and gives their families the peace of mind that they honored their loved one's final wishes." *Id.* *See generally* Wechkin et al., *supra* note 7, at 626 (outlining VSED guidelines and ethical considerations).

[76] *See* McGee & Miller, *supra* note 70, at 3 (discussing VSED and patient autonomy). Physicians using VSED as palliative care do not accelerate the patient's death beyond how the patient is already accelerating it themselves. *Id.* The physician does not provide any sort of medication to the patient to accelerate the end of their life as they would with physician-assisted suicide. *Id.* Rather, the physician is respecting the competent patient's autonomous decision to end their life. *Id.*

[77] *See Clinical Guidelines for VSED*, *supra* note 7, at 626 (explaining guidelines for VSED). There are safeguards in place that ensure VSED is being used ethically. *Id.* Not just anyone can pursue VSED. *Id.* To show an individual has the capacity to pursue VSED, they must indicate certain things. *Id.* An individual must demonstrate an understanding of their diagnosis and prognosis absent VSED, the physical effects of VSED and their management, consistency in the decision over time, and the social and emotional consequences of that decision. *Id.*

> [Decision-making capacity] is required for a patient to begin VSED. Ethical concerns increase when DMC is unclear, such as in the case of mental health disorders, especially if not optimally treated. Clinicians must verify that the patient truly understands the diagnosis, as well as the risks, benefits, and

ethics: that VSED is inherent in each person's right of autonomy over their own body.[78] This rationale builds on the views of Kant and Mills that: "[A]ll persons have intrinsic and unconditional worth" and "should be allowed to exercise [their] capacity for self-determination."[79] As noted by Paul T. Mentzel, Professor Emeritus and Faculty Fellow, Pacific Lutheran University and VSED ethics expert: "[The principle of patient autonomy... bids us to respect the capacity of individuals to choose their own vision of the good life and act accordingly and to engage the patient's own powers of deliberation, choice and agency."[80]

Ethicists also note that the right of autonomy over one's body has heightened meaning in a twenty-first century world of chronic disease and medically managed deaths.[81] As Atul Gawande, physician, public health advocate, and best-selling author, writes:

> You don't have to spend much time with the elderly or those with terminal illness to see how often medicine fails the people it is supposed to help. The waning days of our lives… are spent in institutions— nursing homes, and intensive care units—where regimented, anonymous routines cut us off from all the things that matter to us in life. Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology and strangers.[82]

This twenty-first century reality raises the question: Is it possible that living too long is greater harm than dying too soon? According to Professor Lance Stell, Director of Medical Humanities at Davidson College, the answer is yes: "Common sense

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> alternatives to VSED. When evaluating a request to provide clinical support for VSED, a clinician should seek to understand the patient's reasons for considering VSED. The clinician should con rm that the patient is not being coerced, and that VSED is aligned with the patient's own values.

Id.

[78] *See* MILL, *supra* note 59 (explaining autonomy over one's body); *see also* Schwarz, *supra* note 33; Gruenewald *supra* note 7.

[79] *See* FULLER, *supra* note 61; MILL, *supra* note 59 (describing Mill's theory of autonomy); KANT, *supra* note 63.

[80] *See* VSED TREATISE, *supra* note 31, at 61 (describing principle of patient autonomy); *see also* Varkey, *supra* note 58; TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 162-164 (Oxford Univ. Press 2009); Richard A. Mularski et al., *Pain Management Within the Palliative and End-of-Life Care Experience in the ICU*, 135 CHEST, 1360, 1360 (2009) (explaining end of life care in intensive care unit). Care in the ICU should "provide optimal pain management and palliative care." Mularski et al., *supra*, at 1360. Commonly many patients experience discomfort in the ICU during their end-of-life time. *Id.*

[81] *See, e.g*, Ezekiel J. Emanuel, *Why I Hope to Die at 75*, ATLANTIC (Oct. 2014), https://www.theatlantic.com/magazine/archive/2014/10/why-i-hope-to-die-at-75/379329/ [https://perma.cc/GSZ2-HU3M] (explaining doctor and medical ethicist argues life after 75 is not worth living); DAN W. BROCK, LIFE AND DEATH: PHILOSOPHICAL ESSAYS IN BIOMEDICAL ETHICS (Douglas MacLean ed., Cambridge Univ. Press 1993); DANIEL P. SULMASY, THE HEALER's CALLING: A SPIRITUALITY FOR PHYSICIANS AND OTHER HEALTH CARE PROFESSIONALS (Paulist Press 1997).

[82] *See* ATUL GAWANDE, BEING MORTAL: MEDICINE AND WHAT MATTERS IN THE END 9 (2014) (explaining how medicine has often failed individuals with terminal illnesses). During the last stages of a terminal illness, patients' basic comforts are neglected and they spend their last days in institutions. *Id.*

supports thinking that dying too late can be a harm just as dying too soon can be. If so, death can benefit the one who dies. When death is the least-bad thing that can happened to a person, and nothing better can happen to him, it benefits him."[83] The vast majority of Americans agree with Professor Stell.[84] Indeed, a 2024 Gallup poll showed that 71% of Americans support allowing patients with debilitating, incurable illness to end their lives.[85] Some may agree with this position; some may disagree, but that is the point of normative ethics: each individual is entitled to make this decision for themselves.

Recognition of patient autonomy in health care decisions was established early in American jurisprudence.[86] In *Schloendorff v. Society of the New York Hospital*, a patient brought suit against a hospital in 1914 after she underwent surgery without her consent, resulting in complications causing gangrene and amputation of her fingers.[87] Justice Cardozo, writing for the court, affirmed the patient's right to bring the lawsuit, stating: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."[88] Since *Schloendorff*, the principle of patient autonomy has been the legal bedrock of patient care in the United States.[89]

Ethicists further note that to prevent a patient from engaging in VSED, a health care provider would have to violate the patient's bodily autonomy.[90] The only way to

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[83] *See* LANCE K. STELL, PHYSICIAN-ASSISTED SUICIDE: TO DECRIMINALIZE OR TO LEGALIZE, THAT IS THE QUESTION, *in* PHYSICIAN ASSISTED SUICIDE: EXPANDING THE DEBATE 225 (Margaret P. Battin, Rosamund Rhodes, & Anita Silvers eds., 1998) (describing how death can benefit dying individual).

[84] *See id.*; *see also* Rachel Yi, *Most Americans Favor Legal Euthanasia*, GALLUP NEWS (Aug. 8, 2024), https://news.gallup.com/poll/648215/americans-favor-legal-euthanasia.aspx [https://perma.cc/S3BP-4CGT] (explaining support for doctor assisted suicide).

[85] *See* Yi, *supra* note 83. "Just over seven in 10 Americans, 71%, believe doctors should be 'allowed by law to end the patient's life by some painless means if the patient and his or her family request it.'" *Id.* Many American individuals support end-of-life options. *Id.*

[86] *See* VSED TREATISE, *supra* note 31 (describing patient autonomy).

[87] *See* Schloendorff v. the Soc'y of the New York Hosp., 105 N.E. 92, 93 (N.Y. 1914). Plaintiff visited the New York Hospital in 1908 complaining of abdominal issues. *Id.* Under the care of the hospital's physicians for some weeks, they discovered the Plaintiff had a fibroid tumor. *Id.* One physician advised Plaintiff she needed to undergo an ether examination, to which the Plaintiff consented. *Id.* Plaintiff declined to undergo an operation, nevertheless, the surgeons continued to operate while she was unconscious. *Id.* Plaintiff suffered from gangrene and required finger amputation after the operation, and she filed suit against the hospital for liability of the wrong. *Id.* The court ultimately did not hold the hospital liable but determined the physicians should not have completed the operation without consent. *Id.* at 93-94.

[88] *See id.* at 93. Justice Cardozo explains that every adult of sound mind has the right to the autonomy over their own body. *Id.*; *see also Schloendorff v. New York Hospital and Informed Consent*, LEGAL CLARITY (July 20, 2025), https://legalclarity.org/schloendorff-v-new-york-hospital-and-informed-consent/ [https://perma.cc/5ABU-UUDZ] [hereinafter *Schloendorff and Informed Consent*] (explaining landmark case for informed consent). The opinion in *Schloendorff* outlines the principle of patient autonomy. *Schloendorff and Informed Consent*, *supra*. Justice Cardozo states that a surgeon who performs an operation without a patient's consent commits assault. *Id.*

[89] *See Schloendorff and Informed Consent*, *supra* note 87. *Schloendorff* provides the basis for the principle of informed consent. *Id.* The opinion supports a patient's right to refuse treatment, which has since evolved into the requirement of informed consent. *Id.* The statements in favor of bodily autonomy lay the groundwork for modern ethical and legal standards in medicine. *Id.*

[90] *See Clinical, Ethical, and Legal Aspects of VSEP*, *supra* note 53, at 125 (describing VSED legal considerations). Patients have a right to refuse unwanted bodily intrusions such as medical interventions. *Id.* Physicians must respect a patient's right to refuse medical interventions such as artificial nutrition and hydration. *Id.* Justice Rehnquist observed that bodily integrity is

stop an individual who is determined to cease intake of food and fluid, is to insert an artificial hydration and nutrition tube (a nasogastric tube) through the person's nose, throat, and esophagus into their stomach, against their will.[91] This is the crime of battery (and/or assault) because it is done against a person's will and without their consent.[92]

Justice Sandra Day O'Connor graphically describes the nasogastric tube procedure in *Cruzan v. Director, Missouri Department of Health*, where the Court held that the parents of a twenty-five-year-old woman left in a permanent comatose state after a car accident had the right to require removal of a nasogastric tube from their daughter:

> Feeding a patient by means of a nasogastric tube requires a physician to pass a long flexible tube through the patient's nose, throat, and esophagus and into the stomach. Because of the discomfort such a tube causes, "many patients need to be restrained forcibly and their hands put into large mittens to prevent them from removing the tube."… A gastrostomy tube… or jejunostomy tube must be surgically implanted into the stomach or small intestine….[93]

Justice O'Connor makes clear that such an act violates a person's rights under the U.S. Constitution:

> Requiring a competent adult to endure such procedures against her will burdens the patient's liberty, dignity, and freedom to determine the course of her own treatment. Accordingly, the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment, including the artificial delivery of food and water.[94]

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violated by as little as "sticking a spoon in your mouth." *Id.* at 126. Clinicians should not attempt to feed a patient without consent, if the patient considers being fed harmful or offensive. *Id.*

[91] *See id.* at 126 (explaining patient's right to refuse medical intervention while engaging in VSED). Patients may refuse any bodily intervention, and clinicians must respect those decisions. *Id.*; *see also* Leslie Rodrigues, Su Mon Hein, & Benson Benjamin, *Nasogastric Tube Feeding in Dementia: An Ethical Consideration*, PROGRESS NEUROLOGY & PSYCHIATRY, Sep. 10, 2024, at 1, 2 (explaining ethics of nasogastric feeding tubes). Inserting a nasogastric feeding tube is an invasive procedure. Rodrigues, Hein, & Benjamin, *supra*. The clinician inserts the tube through the patient's nostril, down the esophagus, and into the stomach. *Id.* at 1. Complications often arise from possible infections, risk of tube blockages and infections. *Id.* at 2. Before inserting a nasogastric feeding tube, clinicians should seek a patient's consent. *Id.*

[92] *See* McGee & Miller, *supra* note 70, at 2. Refusing to allow a patient to engage in VSED and non-consensually force feeding them constitutes a battery under the law. *Id.* Individuals have a right to engage in VSED as it is grounded in bodily autonomy. *Id.* The law provides no basis for intervening with a patient engaged in VSED through forced artificial nutrition and hydration. *Id.* A patient has full autonomy to refuse such medical intervention. *Id.*

[93] *See* Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring) (explaining nasogastric tube procedures). Inserting a nasogastric tube causes discomfort and some patients require forced restraint during the procedure. *Id.* Forcing a nasogastric tube on a competent patient that has not consented violates their personal dignity, liberty, and bodily autonomy. *Id.* The Due Process Clause of must protect a person's right to refuse medical treatment, including a refusal of artificial nutrition and hydration. *Id.*

[94] *Id.*

To prevent a patient from removing this tube, it is necessary to commit another crime upon them: unlawful restraint, either physically or chemically.[95] Because both insertion of a tube and restraint of a patient are medical procedures, they will need to be performed by health care professionals who may subject themselves to criminal and civil legal liability, as well as loss of medical license by performing these procedures.[96] Ethicists reason that the draconian nature of the steps required to stop a person from VSED reinforces the conclusion that VSED is the right of every competent adult over their own body.[97]

V. Part Four: Clinicians' Ethical Duties to VSED Patients

This section addresses four duties of clinicians regarding VSED patients: (1) the duty to make pre-VSED assessments of individuals considering VSED; (2) the duty, largely through these assessments, to ensure VSED is not foisted on dependent and unwilling individuals; (3) the duty to provide patients with information about VSED; and (4) the duty to provide care to VSED patients.

A. Clinicians' Duties Regarding Pre-VSED Assessments

The *Clinical Guidelines for VSED* require that three assessments be made by a clinician before a person proceeds with VSED.[98] These assessments are competency, voluntariness, and presence of suffering.[99]

i. Assessing Competency

The right of patients to control their own health care decisions affecting their own bodies does not extend to persons who lack cognitive capacity.[100] Thus, best

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[95] *See* McGee & Miller, *supra* note 70, at 2. A patient of sound mind engaging in VSED has a right to noninterference. *Id.* Force feeding would constitute a personal assault if a patient refuses it. *Id.*; *Clinical, Ethical, and Legal Aspects of VSEP*, *supra* note 53, at 126. A clinician violates bodily integrity with any form of nonconsensual touching. *Clinical, Ethical, and Legal Aspects of VSEP*, *supra* note 112, at 126.

[96] *See* Andi Mirza, Dahlan, & Teuka Muttaqin Mansur, *Criminal Liability of Perpetrators of Health Care Malpractice*, 2 Int'l J. L. & Soc'y 238, 239 (2025) (describing elements of criminal liability for doctors charged with malpractice). Assessing criminal liability for doctors accused of malpractice hinges on the two elements of guilt and the causal relationship between the acts performed by the doctor and the injuries associated. *Id.*; Zaid Ibrahim Yousef Gharaibeh, *The Impacts of Applications of Criminal Law on Medical Practice*, 76 Med. Archives 377, 380 (2022) (detailing precarious position doctors face regarding civil and criminal liability). The recent trend of over diagnosing patients and providing unnecessary healthcare provides more opportunities for medical professionals to be accused of malpractice. Gharaibeh, *supra*.

[97] *See* VSED Treatise, *supra* note 31 (describing steps required to stop VSED process).

[98] *See* Wechkin et al., *supra* note 7, at 628 (describing ethical requirements before allowing VSED). Clinicians must additionally review the process with the candidate, advise those who regularly drink alcohol of withdrawal symptoms, and inform the candidate of the possibility of delirium. *Id.* Delerium poses a particular concern, considering that a candidate's request for water or food to curtail the delirium will prolong the VSED process and put clinicians in an ethical quandary. *Id.*

[99] *See id.* (enumerating assessments performed by clinician prior to VSED). Clinicians must consider that a patient's deteriorating mental state may give them a dwindling window of time in which the patient will have the required mental capacity to consent to VSED. *Id.* Clinicians should determine capacity "markers" with the patient which signal the time to start VSED, such as physical ability and degree of pain. *Id.*

[100] *See, e.g.*, *id.* at 626 (requiring clinicians to determine that patient understands specifics of VSED). Clinicians must seek to understand the reason a patient has for requesting VSED. *Id.*

practices and clinical guidelines call on clinicians to determine that when individuals with dementia seek VSED, they are found to retain cognitive capacity necessary to make an end-of-life decision such as VSED.[101] As outlined by Drs. Gruenewald and Vandekieft, and set forth in the *Clinical Guidelines for VSED*, a pre-VSED assessment of cognitive capacity should be made of any patient considering VSED.[102] The assessment should include "…verification that the patient truly understands the diagnosis, as well as the risks, benefits, and alternatives to VSED."[103]

ii. Assessing Voluntariness

The assessment of voluntariness centers on four questions.[104] The first is whether the person choosing VSED has a full understanding of their disease and the VSED process.[105] The second is whether a person's VSED decision is prompted by depression or mental illness.[106] The third is whether outside pressure, directly or indirectly, influences a person to choose VSED.[107] The fourth is whether an individuals' VSED decision is consistent with the values the person has held throughout their life. This fourth assessment helps prevent impulsive actions. Patient and family interviews, as well as medication reviews, are relevant in making these assessments.[108]

iii. Assessing Suffering

Clinicians must confirm that VSED is in harmony with the patient's values, and that they have not been coerced. *Id.*; *see also* Varkey, *supra* note 58, at 19 (describing requirements of informed consent for medical procedures). The requirements for medical informed consent are ". . . that the patient or subject (i) must be competent to understand and decide, (ii) receives a full disclosure, (iii) comprehends the disclosure, (iv) acts voluntarily, and (v) consents to the proposed action." Varkey, *supra* note 58, at 19.

[101] *See Gruenewald, Long-Term Care Facilities*, *supra* note 37, at 1216-17 (discussing necessity of patients with cognitive decline to fully understand decision of VSED). Evidence that a patient still retains the cognitive ability to consent to VSED includes the ability to reason about benefits and risks, and the ability to communicate their choice. *Id.* at 1217; Gruenewald & Vandekieft, *supra* note 7.

[102] *See* Wechkin et al., *supra* note 7, at 626 (mandating clinicians determine patient can comprehend severity of decision). Ethical concerns may emerge when patients have a diagnosis of a mental health disorder, which may render their decision-making capacity to be insufficient. *Id.* Clinical guidelines strongly suggest clinicians consult specialists in psychiatry and palliative medicine when ethical ambiguities arise. *Id.* at 627; *see also* Gruenewald & Vandekieft, *supra* note 7 (detailing need for pre-VESD assessment).

[103] *See* Gruenewald & Vandekieft, *supra* note 7, at 542-43; *see also* Wechkin et al., *supra* note 7, at 626 (describing requirement of clinician to ensure patient understands ramifications of VSED). Clinicians should understand the patient's reasons for requesting VSED, to determine if mental health counseling or spiritual intervention may be more appropriate. Wechkin et al., *supra* note 7, at 626.

[104] *See* Wechkin et al., *supra* note 7, at 626 (discussing situations in which patient's makes involuntary). Certain patients have created short videos recorded at the outset of VSED to remind them why they made their decision, in case they become anxious once VSED has commenced. *Id.* at 630. Additionally, if there are concerns that certain family or friends may wish to sabotage the VSED process, the authors encourage legal consultation before undergoing VSED. *Id.* at 628.

[105] *See* Wechkin et al., *supra* note 7, at 626 (describing first step in VSED voluntariness assessment).

[106] *See id.* (outlining second step in VSED voluntariness assessment).

[107] *See id.* (indicating third step in VSED voluntariness assessment).

[108] *See id.* at 626-27 (discussing additional relevant criteria in VSED voluntariness assessment) and 636 (highlighting importance of patient values and voluntariness in VSED decision analysis).

The *Clinical Guidelines for VSED* make clear that VSED is not clinically appropriate for individuals with potentially curable or manageable diseases that could be addressed with treatment.[109] VSED is for patients suffering severely from an incurable, progressive disease. The *Guidelines* state: "VSED is legal in the United States and may be undertaken by patients with a clearly-defined terminal illness associated with a prognosis of months to several years. It may also be sought by a patient who has a diagnosis, such as dementia, that is associated with progressive decline and a prognosis of many years as well as an anticipated quality of life deemed by the patient to be unacceptable."[110]

Alzheimer's disease presents two unique factors in examining the "suffering" prerequisite for VSED.[111] The first is the extended length and nature of Alzheimer's disease.[112] As noted, Alzheimer's is considered the most-feared of all diseases because of what it does to a person -- it destroys a person's sense of self, leaving those with it unaware of who they are and who they have been, dependent on others for every need.[113] This suffering is made worse because Alzheimer's patients typically live in this state for years.[114]

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[109] *See id.* (asserting some patients ineligible for VSED).
[110] *See id.* (identifying suitable patient candidates for VSED).
[111] *See id.* (defining VSED); *see also* Cynthia A. Meier & Thuan D. Ong, *To Feed or Not to Feed? A Case Report and Ethical Analysis of Withholding Food and Drink in a Patient With Advanced Dementia*, 50 J. PAIN & SYMPTOM MGMT. 887, 889 (2015) (examining ethical dilemma of VSED).

> As dementia progresses, patients undergo progressive and profound cognitive and personality changes. The literature has made a distinction between the "then" self, the person before the progression of dementia, and the "now" self, the person with cognitive impairment and who lives almost entirely in the present. If there is discord between the wishes of the "then" self and the "now" self, there is no consensus in the literature about which self should be honored.

Meier & Ong, *supra*.
[112] *See* Wechkin et al., *supra* note 7, at 626 (explaining complex nature of Alzheimer's disease). VSED raises more ethical concerns when patients have a greater natural life expectancy. *Id.*
[113] *See Over half of people fear dementia diagnosis, 62 per cent think it means 'life is over,'* ALZHEIMER'S SOC'Y (May 13, 2016), https://www.alzheimers.org.uk/news/2025-10-08/over-half-people-fear-dementia-diagnosis-62-cent-think-it-means-life-over [https://perma.cc/5VNE-SCFP] (highlighting reasons people fear Alzheimer's disease). *See also* Milken Inst., *supra* note 21. *See generally* Wechkin et al., *supra* note 7, at 626 (noting various VSED qualification requirements); Barry Reisberg, *Clinical Stages of Alzheimer's*, FISHER CTR. FOR ALZHEIMER'S RSCH. FOUND., https://www.alzinfo.org/pym/feature/clinical-stages-alzheimers-disease/ [https://perma.cc/7L74-YQC6] (describing Alzheimer's clinical stages). Dr. Reisberg, serving as the Clinical Director of New York University's Aging and Dementia Research Center, provides the seven major clinical stages of Alzheimer's. Reisberg, *supra*. In doing so, Dr. Reisberg is able to express the overall effects and constant decline that disrupts quality of life for patients and highlights the specific burdens they may experience at that point. *Id.*; *see also* ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 3, at 5 (describing Alzheimer's statistics).
[114] *See* Reisberg, *supra* note 112 (analyzing last stages of Alzheimer's disease). This last stage exhibits a severe form where AD patients require continuous assistance with even the most basic activities of daily life to maintain survival. *Id.* Within each stage, there is also the existence of substages that present their own sets of decline on the body and outline the necessary support patients must receive during this period. *Id.* With the appropriate care and life support, patients may survive in this final stage of AD for a period of years. *Id.*

The second feature of Alzheimer's disease that impacts the assessment of suffering is the closing window of competency facing those with it. Most individuals with Alzheimer's will lose cognitive competency in stage four or five of Alzheimer's, but beyond this, they do not know when.[115] Their cognitive capacity could end quickly and unexpectedly as with a bout of flu or a change in routine, or it could not happen for months, even years.[116] This uncertainty compounds the suffering for those with dementia who plan to VSED because of the constant and wrenching calculus they face: Do I start VSED now, when I still have a good quality of life and possibly years of competency left, or do I wait and risk getting a sudden illness and lose the ability to choose VSED? How do I know when it is time?

Cindy, the palliative care physician who was diagnosed with Alzheimer's disease and set forth her VSED plan in her advance directive, wrote of this anguish:

> It will always be too early in the judgment of some people who are not living my life. So, I am going to start VSED when I feel ready even though it may seem too early to some friends or family members. I don't want to miss my window of opportunity. Again, my choice is to have a few quality days with loved ones in order to maintain control of my life and prevent unnecessary suffering for me and for them. That is what makes my life worth it to me. [117]

B. Clinicians' Role in Ensuring that VSED is Not Foisted Upon Dependent Individuals

In early academic literature, before the safeguards for VSED were developed, concerns were raised that VSED "devalues the lives of people with disability and implicitly suggests that their lives are less valuable or even expendable" and may be intentionally or otherwise imposed on disabled individuals.[118] As one author wrote: "Such an idea may seem preposterous, but history teaches us this is exactly what happened in Nazi Germany."[119] Even though safeguards exists to prevent this from happening, this concern has been raised by some, especially by those who are

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[115] *See id.* (explaining Alzheimer's stage four and five competency issues).

[116] *See id.* (identifying possible cognitive decline timelines); *Cognitive Issues in Alzheimer's*, ALZ (Dec. 2025), https://alzheimersdisease.net/symptoms/memory-loss [https://perma.cc/LN8M-MCVJ] (noting cognitive decline variability). In addition to the varying timelines of cognition decline, Alzheimer's patients may also present cognitive decline differently. *Cognitive Issues in Alzheimer's*, *supra*. Some symptoms can present decision-making troubles, or more extreme language deficits. *Id.*

[117] *See* END OF LIFE WASHINGTON, *Cindy's VSED Statement*, at 9:24 (YouTube, Aug. 16, 2022), https://www.youtube.com/watch?v=ed0ti0PUGSk [https://perma.cc/LWA3-TKT4] (explaining VSED advance directive plan importance).

[118] *See* Tim Stainton, *Disability, Vulnerability and Assisted Death: Commentary on Tuffrey-Wijne, Curfs, Finlay and Hollins*, BIOMED. CTR. MED. ETHICS, Nov. 27, 2019, at 1, 3 (explaining prior concerns with VSED). Recent reports have indicated that the lives of those with intellectual disabilities are undervalued across society, and their shorter life expectancy may be partly due to poor decision-making by their healthcare professionals. *Id.*

[119] *See Cf.* John Harwig, *Is There a Duty to Die?*, 27 HASTINGS CTR. REP. 34, 39 (1997) (describing intellectually incompetent individuals' worry of becoming burdensome to family). While some individuals experiencing illness-induced intellectual decline feel guilty for becoming a burden on their friends and family, society is reluctant to allow doctors or anyone else to aid in life-ending treatment. *Id.*

unfamiliar with VSED or its required safeguards.[120] As one of my elderly friends remarked: "How do we know that someone is not going to go into nursing homes and point to one elderly, feeble person after another and say, 'no food or fluid for you, or you, or you.'"

The concern of depriving dependent persons of needed and desired sustenance deserves discussion. There are three responses to it. The first response is that if anyone deprives another person of food and fluid against the person's wishes, that is not VSED.[121] VSED is *voluntarily* stopping eating and drinking.[122] Neglecting to provide food or fluid to a dependent person against their will is not VSED.[123] Forcibly preventing a person from eating or consuming fluid is not VSED. These acts are abuse and potentially homicide.[124]

The second response is recognizing the difference between MAID and VSED.[125] There are vocal critics of MAID among physically and intellectually disabled individuals and their advocates.[126] Their concern is that MAID will be forced, directly or indirectly, on disabled persons. But VSED is different than MAID in crucial ways that address this concern.

The first difference is how quickly the act of MAID occurs compared to the act of VSED.[127] While there are multiple steps and timelines required for a patient to be

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[120] *See* Wechkin et al., *supra* note 7, at 629 (outlining VSED guidelines and elaborating on clinical guidelines for VSED); Ayesha Munir et al., *Voluntarily Stopping Eating and Drinking: Navigating the Challenges When Prognosis is Uncertain*, 69 J. PAIN & SYMPTOM MGMT. e724, e724 (2025) (highlighting ethical issues surrounding VSED).

[121] *See Voluntarily Stopping Eating and Drinking (VSED)*, END OF LIFE CHOICES N.Y., https://endoflifechoicesny.org/vsed-voluntarily-stopping-eating-drinking/ [https://perma.cc/WY2Q-CRQT] (defining VSED). VSED is a voluntary decision made by a competent adult to permanently stop the intake of food and fluids with the goal of accelerating death. *Id.* The decision to undergo VSED must be non-coerced and made by the individual who intends to undergo VSED if they suffer from an incurable or terminal illness. *Id.*

[122] *See id.* (explaining voluntariness of VSED); Wechkin et al., *supra* note 7, at 625 (identifying voluntariness in definition of VSED).

[123] *See* Wechkin et al., *supra* note 7, at 625 (articulating voluntariness as part of VSED); *see also Voluntary Stopping of Eating and Drinking (VSED)*, VT. ETHICS NETWORK, https://vtethicsnetwork.org/medical-ethics/voluntarily-stopping-eating-and-drinking [https://perma.cc/3KY6-69UD] (explaining VSED process). Even if an individual who decides to pursue VSED is in an inpatient facility, medical staff do not aid in or provide the means for the patient to hasten death. *Voluntary Stopping of Eating and Drinking (VSED)*, *supra*. Both the decision to refuse nourishment and the subsequent means for carrying out that decision is completely in the patient's hands. *Id.*

[124] *See Voluntary Stopping of Eating and Drinking (VSED)*, *supra* note 122 (discussing VSED).

[125] *See* Timothy E. Quill, Editorial, *Voluntary Stopping Eating and Drinking (VSED), Physician-Assisted Death (PAD), or Neither in the Last Stage of Life? Both Should Be Available as a Last Resort*, 13 ANNALS FAM. MED. 408, 409 (2015) [hereinafter *VSED, PAD, Both Should Be Available as a Last Resort*] (distinguishing between VSED and physician-assisted death concluding both warrant independent ethical and clinical consideration).

[126] *See* Robert L. Burgdorf Jr., NAT'L COUNCIL ON DISABILITY, *Assisted Suicide: A Disability Perspective Position Paper* (1997) (documenting strong and organized position on PAD among disability communities and advocates). The advocates that are opposed to PAD have concerns rooted in the idea that such laws pose a disproportionate threat to those people with disabilities. *Id.*; Jack Butler, *Kathy Hochul Faces a Life-or-Death Decision*, WALL ST. J. (Dec. 12, 2025), https://www.wsj.com/opinion/kathy-hochul-faces-a-life-or-death-decision-afb2a737 [https://perma.cc/4CWB-4MXG] (examining Governor Hochul's pending decision whether to sign New York's Medical Aid Dying Act).

[127] *See VSED, PAD, Both Should Be Available as a Last Resort*, *supra* note 124, at 409 (comparing distinctiveness of PAD and VSED end-of-life options). The significant differences in these

approved for MAID, the actual act causing death—self-ingestion of a lethal medication—takes place in the seconds it takes to swallow medication.[128] Because this act is immediate, it is conceivable, even if remotely so given the safeguards required for MAID, that a person could be pressured, forced, or guilted in those few seconds into swallowing the lethal medication.

In contrast, VSED does not take place in seconds.[129] It takes place over days, weeks.[130] It requires sustained commitment, tremendous self-will, and powerful self-discipline—hour after hour, day after day.[131] No amount of pressure could possibly induce a person to stick with VSED for the length of time VSED takes.[132] In this sense the logistics of VSED, which can be complex to navigate, prove to be a crucial safeguard against possible pressure or influence by others. This factual difference in MAID and VSED is, in fact, one of the reasons many individuals, including clinicians, find VSED morally and ethically preferable to MAID.[133]

The third response to the concern that VSED might be foisted on dependent persons is recognizing that a powerful way to prevent such abuse is by educating the public and the health care profession about VSED and its safeguards. Greater awareness of VSED not only helps those who seek its relief and peace but also helps identify instances where abuse may be occurring.

C. Clinicians' Duty to Provide Information About VSED to Patients

Health care professionals are ethically obligated to inform their patients of relevant health care information.[134] This is to help patients make informed decisions: "Respecting the principle of autonomy oblige the physician to disclose medical information and treatment options that are necessary for the patient to exercise self-determination and supports informed consent, truth telling, and confidentiality."[135]

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end-of-life options begin with how the process unfolds starting from the speed and timeline of each of these processes. *Id.*

[128] *See id.* (comparing procedural timelines of PAD and VSED). While there are significant differences between the two processes, the significant difference lies in PAD culminating in a single discrete act of ingestion as opposed to VSED which is a significantly longer, more grueling process. *Id.*

[129] *See VSED, PAD, Both Should Be Available as a Last Resort*, *supra* note 31 (describing VSED including process unfolding over days to weeks, requiring continuous volitional effort by patient).

[130] *See id.*

[131] *See id.*

[132] *See* Paul T. Menzel, *Voluntarily Stopping Eating and Drinking: A Normative Comparison with Refusing Lifesaving Treatment and Advance Directives*, 45 J. L., MED. & ETHICS 634, 635 (2017) (analyzing inherently self-directed nature of VSED and explaining why duration renders external coercion practically impossible).

[133] *See* Quill et al., *supra* note 31 (examining moral and ethical distinctions between VSED and PAD); *see also* Lachman, *supra* note 35, at 57 (arguing VSED morally and ethically preferable to PAD). VSED is considered preferable in part because the patient has a sustained and active role throughout the dying process. Lackhman, *supra* note 35, at 57.

[134] *See* Wechkin et al., *supra* note 7, at 625 (establishing clinical obligation to inform patients of relevant end-of-life options). Healthcare professionals are ethically obliged to inform patients of relevant health care information, particularly VSED as an option for end-of-life-care. *Id.*

[135] *See* Varkey, *supra* note 58, at 19 (expanding on physicians respecting patient autonomy). Physicians must help the patient comprehend the full disclosure of a medical diagnosis or treatment so they can act voluntarily and consent to the proposed action. *Id.* An autonomous patient has the right to know their diagnosis and treatment plan and that they have the option to forgo the disclosure. *Id.* Historically, no legal or regulatory authority requires physicians to fully disclose diagnoses, called truth telling, to their patients. *Id.* at 20; *see also* Schlendorf v. Soc'y of

Information about VSED, a legal, ethical, and peaceful end-of-life option, is obviously relevant information to a patient who is terminally ill or suffering from an intractable disease such as Alzheimer's or other dementia who initiates a conversation about hastening death or specifically inquiries about VSED.

In their article, *Options of Last Resort*, Drs. David Gruenewald and Gregg Vandekieft provide protocols and best practices for health care professionals in talking with patients about VSED.[136] These protocols are activated when a patient has initiated a conversation about hastening death or specifically inquiries about VSED.[137] Clinicians and ethicists consistently find that the obligation to inform patients about VSED under these circumstances extends to providers whose personal beliefs conflict with VSED.[138]

But what about the situation when a patient does not initiate such a conversation? What if they don't know to ask about VSED? What if they are still reeling from their Alzheimer's diagnosis and unable to think through something as serious as end-of-life options? This is when the health care provider's ethical duty to provide relevant information to patients becomes more complex.

On the one hand, because current, accurate information about VSED can be difficult to find and process, it is important that trained health care providers provide this information. Most patients are inadequately skilled in medicine to fully decipher information about a medical topic as complex as VSED.[139] In addition, the circumstances making VSED relevant in a person's life may well be emotionally fraught for the person and their family. It is such circumstances that patients most need a clinician's guidance.

On the other hand, providing end-of-life information is ethically and legally challenging for health care providers because they cannot catalyze a patient's decision to choose VSED or any end-of-life option, or be viewed by a patient or their family as encouraging such a decision.[140] Providing end-of-life information is especially

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N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914) (establishing legal bedrock of principle of patient autonomy).

[136] *See* Gruenewald & Vandekieft*, supra* note 7, at 540-41 (providing guidelines for best communication practices between physicians and patients).

[137] *See id.* (emphasizing patient's initiation in conversing with physician).

[138] *See Gruenewald, Long-Term Care Facilities*, *supra* note 37, at 1217 (recommending solutions for physicians struggling with moral conflict); *see also* Schwarz, *supra* note 33, at 129 (finding balance between moral beliefs and medical obligation). Clinicians are not required to act against their own moral or religious belief, but they must inform their patients about all legally available options. Schwarz, *supra* note 33, at 129. Clinicians must provide information and support for all legal medical options before they withdraw themselves from the case. *Id.*; Lachman, *supra* note 35, at 57 (noting obligations of nurse informing patients). Nurses have an obligation to inform patients of all options to help them understand the benefit, burden, and the consequences of hastened death. Lachman, *supra* note 35, at 57. Similar to a physician, a nurse can voice their objection when their moral integrity feels compromised and ask for a replacement in the care of the patient. *Id.*

[139] *See* Wechkin et al., *supra* note 7, at 626 (emphasizing complexity in lack of real-time decision-making capabilities). To demonstrate a capacity to pursue VSED, a patient must understand their diagnosis and prognosis without VSED, the physical challenges, and the social and emotional challenges of VSED. *Id.* To prepare for VSED, patients undertake a series of preparatory steps, including obtaining medical consultations, hospice referrals, and legal counsel, procuring necessary supplies and equipment, hiring caregivers, and notifying family members and friends. *Id.*

[140] *See* Gruenewald & Vandekieft, *supra* note 7, at 540-41 (recommending guidelines for best communication practices for physicians to avoid legal complications); *see also* Wechkin et al., *supra*

challenging when patients have Alzheimer's or a related dementia and begin to lose cognitive capacity before their diagnosis and before they can legally and ethically make an end-of-life decision.

Unfortunately, late or inaccurate diagnosis of Alzheimer's or a related dementia is too common in the United States. This is true for multiple reasons. There is a lack of health care providers in the U.S. who are trained in detecting and treating Alzheimer's or other dementias. There is a lack of awareness by the general public of early signs of dementia. There is significant stigma and fear surrounding a possible dementia diagnosis that discourage patients from confiding symptoms to family or clinicians. The result is that too many individuals who are diagnosed with dementia are close to, or past, the point of cognitive competency when they get their dementia diagnosis.[141] Data worldwide shows that the majority of individuals living with dementia have not received a formal diagnosis.[142] Even "in high income countries, only 20-50% of dementia cases are recognized and documented in primary care."[143]

When individuals receive their dementia diagnosis shortly before or after they lose cognitive capacity, they do not have time to process the full impact of their diagnosis, much less think through and gather information about end-of-life options before they have to make a VSED decision. Sadly, among these patients may well be some who, unquestionably, would have chosen VSED if they had known about it earlier.

The question is whether this reality coupled with the fact that VSED, which requires cognitive capacity, is the only realistic and lawful end-of-life option available to individuals with Alzheimer's or dementia diseases, changes the ethical and legal calculus of when and how a provider discusses VSED with a dementia patient. But even so, as a practical matter, how would providers comply with their ethical duty to provide relevant information while not catalyzing or encouraging an end-of-life decision? Could a provider say to a patient: "I'm sorry to have to break the news to you, but you have Alzheimer's disease. Unless you die of something else first, you will be rendered incompetent, incontinent, immobile, unable to communicate, unaware of who you are,

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note 7, at 626 (guiding clinician interactions with patients). Clinicians should confirm that the patient is making a decision that is free of coercion. Wechkin et al., *supra* note 7, at 626.

[141] *See* Spencer Kimball, *Alzheimer's Patients May Wait Years to Get Treated With New Drugs, Putting Them at Risk of More Severe Disease*, CNBC (May 1, 2023), https://www.cnbc.com/2023/04/30/alzheimers-treatment-patients-may-wait-years-for-new-drugs.html [https://perma.cc/JEQ4-8NKF] (finding significant wait time in Alzheimer's diagnoses from lack of qualified physicians). Patients seeking a first visit with a specialist could face an initial wait time of twenty months. *Id.* The delay could increase to four years by 2028 and continue increasing through 2050. *Id.*; *see also* JASON KARLAWISH, THE PROBLEM OF ALZHEIMER'S: HOW SCIENCE, CULTURE, AND POLITICS TURNED A RARE DISEASE INTO A CRISIS AND WHAT WE CAN DO ABOUT IT 83-91 (2021) (determining science, culture, and politics turned rare disease into crisis); Andrea Bradford et al., *Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors*, 23 Alzheimer Disease & Associated Disorders 306, 310 (2009) (claiming stigma of dementia contributes to missed diagnosis). Many patients avoid a diagnosis due to the stigmatizing effects and tend to doubt the efficacy of an early diagnosis. Bradford et al., *supra*.

[142] *See Dementia statistics*, ALZHEIMER'S ASS'N INT'L, https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/ [https://perma.cc/KU9Q-GCZV] (emphasizing importance of official diagnosis). People who do not have a proper dementia diagnosis do not have access to proper treatment, care, and organized support. *Id.*

[143] *See id.* (elaborating on dementia treatment gap). The treatment gap of patients receiving a proper diagnosis is greater in low and middle-income countries. *Id.* One study in India suggests 90% of people are undiagnosed. *Id.* Based on that percentage, approximately three quarters of people with dementia are undiagnosed. *Id.*

or who you have been. You will not recognize loved ones. You will become dependent on others for every aspect of life. You will live this way, bedridden and diapered, for years before you die. And by the way, if you decide to hasten your death, here's something you may want to know about. It's called VSED and realistically, it's your only lawful way of dying if you don't want to die of Alzheimer's disease." There is no way a provider, however delicately, could say this to a patient.

Yet there is a way providers can ethically "thread this needle" and give patients newly diagnosed with Alzheimer's or other dementia and their families information about end-of-life issues and options without catalyzing a decision or overwhelming them. They can do so by including brief end-of-life information in a wide-ranging compendium of resources and information typically given to individuals and families when a person is diagnosed with Alzheimer's or similar dementia.

This packet includes (again, should include) information, checklists, and links to resources that can help patients get their affairs in order. Topics covered include not only medical information about what to expect as their disease progresses but also life-style topics such as: advance planning, financial planning, possible career or housing changes, access to community resources such as day care and respite groups. Including brief information about end-of-life options with references to sources for further information, when provided in the sweeping context of the above topics, would no more imply that a health care provider is endorsing VSED than that the provider is endorsing a specific living arrangement or financial advisor.

Referenced sources in such a compendium can then direct patients and their families to the more detailed information they should consider, such as, for example, that simply stating in an advance directive that they do not want artificial nutrition and hydration may not be adequate to ensure care and support during VSED.[144] Links and references to VSED should include an explanation of the importance of a VSED-appropriate advanced directive if patients plan to VSED as well as templates for such advanced directives. The referenced sources should direct individuals to prepare a video explaining why they chose to VSED, and how they want their health care proxy and caregivers to respond if the patient asks for food or fluid as they become befuddled during their VSED process. Links and references should alert patients to something known as "minimal comfort feeding."[145] This option may be more acceptable to memory care facilities or nursing homes.[146] The drawback to minimal

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[144] *See* Thaddeus M. Pope et al., *New VSED Advance Directive: Improved Documentation to Avoid Late-Stage Dementia*, 53 J. L. MED. & ETHICS 491, 493 (2025) (discussing Nora Harris and Margot Bentley cases). Nora Harris made an advanced directive in 2009, granting her husband the power to refuse artificial nutrition and hydration through a feeding tube. *Id.* The directive did not specifically address oral feeding and drinking. *Id.* Though he directed the care facility to stop spoon-feeding, the husband failed in requesting the facility and court to enforce his wife's wishes. *Id.* The facility continued spoon-feeding Nora Harris until her death in 2017. *Id.* Margot Bentley's directive in 1991 failed to specifically address oral food and drink. *Id.* As a result, the nurses kept her alive by spoon-feeding her and Bentley died seventeen years after her Alzheimer's diagnosis in a non-responsive state. *Id.*

[145] *See* Hope A. Wechkin et al., *"Mr. Smith Has No Mealtimes": Minimal Comfort Feeding for Patients with Advanced Dementia*, 69 J. PAIN & SYMPTOM MGMT. 216, 216 (2025) (discussing new approach and alternative to VSED). Minimal comfort feeding provides only small amounts of food and fluids to maintain a patient's comfort. *Id.* at 218. Caregivers offer food and liquids only when patients show signs of hunger or thirst rather than following scheduled meals. *Id.* They do not wake patients or pressure them to eat; instead, they focus on comfort measures such as careful mouth care, social interaction, therapeutic touch, sensory distraction, and medication to relieve discomfort before offering small amounts of nutrition or hydration. *Id.*

[146] *See id.* at 219 (addressing caregiver concerns). Minimal comfort feeding may require systematic monitoring of the patient and the ability to respond to symptoms. *Id.* The presence of possible

comfort feeding is that it lasts longer than VSED and it is generally deemed relevant after a patient has lost cognitive capacity and entered the later stages of dementia, a condition many individuals seek to avoid through VSED.[147] Although not yet tested in U.S. courts, patients should also be alerted in links and references to the possibility of "VSED by advance directive," which authorizes a health care proxy to begin VSED if the patient later loses cognitive capacity.[148]

In summary, VSED is as important as other "get your affairs in order" information. End-of-life decisions are complex and nuanced. Guidance from a clinician and from reliable resources is as essential as advice on how to get one's financial affairs in order. When a patient specifically inquiries about options to hasten death and thus opens the door for a provider to supply this type of information and helpful resources, the clinician's role is clear: Clinicians are ethically required to provide a patient with relevant information.[149] When patients do not initiate conversation about end-of-life planning or learn of their dementia diagnosis late in their disease, including brief information with resources for further reading in an information packet provided to dementia patients is one way to meet a provider's legal and ethical obligation to provide relevant information to a patient without catalyzing or influencing an end-of-life decision.[150]

D. Clinicians' Duty to Provide Care to VSED Patients

What are health care providers' obligations to render care to a person who has chosen VSED? What are the obligations of providers whose personal beliefs are violated by VSED?

It is well settled that no health care professional is required to provide care to a patient if that care violates the provider's personal beliefs.[151] As provided by the AMA

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thirst and hunger may be difficult to discern, requiring careful observation and knowledge of symptoms. *Id.*

[147] *See id.* at 217 (comparing minimal comfort feeding with VSED). While VSED typically leads to death within days, minimal comfort feeding may extend the process for several weeks to a few months. *Id.* Clinicians consider minimal comfort feeding only when a patient has progressed to advanced dementia and when conversations with the surrogate confirm that the patient previously indicated a desire not to continue living in that condition. *Id.* at 218.

[148] *See* James L. Wright, Peter M. Jaggard, & Timothy Holahan, *Stopping Eating and Drinking by Advance Directives (SED by AD) in Assisted Living and Nursing Homes*, 20 J. AM. MED. DIR. ASS'N 1362, 1362 (2019) (discussing ethical consideration of SED by advanced directive). *See generally* Quill et al., *supra* note 31, at 133-257 (discussing VSED and advanced directives).

[149] *See Opinion 5.1: Advance Care Planning*, AMA CODE MED. ETHICS, https://code-medical-ethics.ama-assn.org/ethics-opinions/advance-care-planning [https://perma.cc/SX5F-MK42] [hereinafter *Opinion 5.1*] (outlining physician's responsibilities when planning advanced care).

[150] *See* Bo Xie et al., *End-of-Life Decision Making by Family Caregivers of Persons with Advanced Dementia: A Literature Review of Decision Aids*, SAGE OPEN MED., Jan.-Dec. 2018, at 1, 2 (reviewing decision aids for people with dementia). As the number of people with dementia at the end of life grows, researchers have developed interventions to help family caregivers navigate complex medical decisions. *Id.* One common approach uses decision aids which are structured tools that provide information about a patient's condition, explain the risks and benefits of treatment options, and help families clarify the patient's values when making care decisions. *Id.* decision aids supplement discussions with healthcare providers and improve knowledge, shared decision-making, and satisfaction with care decisions. *Id.*

[151] *See Opinion 1.1.7: Physician Exercise of Conscience*, AMA CODE MED. ETHICS, https://code-medical-ethics.ama-assn.org/ethics-opinions/physician-exercise-conscience [https://perma.cc/DU7T-EHYS] [hereinafter *Opinion 1.1.7*] (outlining ethical limits on

Principles of Medical Ethics: "A physician shall, in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical care."[152]

There are limitations, however, on this right to "conscientiously object" to providing care to a patient.[153] The first limitation is that health care professionals are not permitted to substitute their personal beliefs for those of a patient: "Clinicians are not required to act against their principles, but they must not make moral judgments for their patients based on their personal beliefs."[154] This includes VSED.[155] Clinical and ethical experts agree: "If the patient independently decided to refuse food and fluids, the physician would have to respect the patient's right to make this decision."[156]

The second limitation on providers' right to conscientiously object to providing patient care is the principle of non-abandonment.[157] No provider is permitted to

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physicians' exercise of conscience); *Clinical, Ethical, and Legal Aspects VSEP*, *supra* note 53, at 124-25.

[152] *See AMA Principles of Medical Ethics*, AMA CODE MED. ETHICS, https://code-medical-ethics.ama-assn.org/principles [https://perma.cc/J75G-5SXR] (permitting physicians to make ethical decisions about whether to provide care and to whom).

[153] *See Opinion 1.1.7*, *supra* note 150 (limiting physicians' ability to object based on conscience).

[154] *See Clinical, Ethical, and Legal Aspects VSEP*, *supra* note 53, at 124-25; *see also* Wechkin et al., *supra* note 7, at 626 (providing guidelines for VSED).

[155] *See Clinical, Ethical, and Legal Aspects VSEP*, *supra* note 53, at 127; *see also Voluntary Stopping Eating and Drinking (VSED): A Viable, Lesser Known Palliative Option for Last Resort*, AM. ACAD. OF HOSPICE & PALLIATIVE MED. LEARN (Aug. 13, 2021), https://learn.aahpm.org/content/voluntarily-stopping-eating-and-drinking-vsed-viable-lesser-known-palliative-option-last [https://perma.cc/25WG-SAM5] (supporting prohibition of health care professionals from imposing personal beliefs in care for patients). While health care professionals are not permitted to substitute their personal beliefs for a patient, physicians should be a central part of the decision-making process to help palliate symptoms and respond to any problems or challenges. AM. ACAD. OF HOSPICE & PALLIATIVE MED. LEARN, *supra*.

[156] *See* McGee & Miller, *supra* note 70, at 2 (stating experts agree on role of physician when patients refuse food and fluids). In the context of VESD, physicians are respecting the patient's autonomous decision. *Id.* at 3. Additionally, it is in the role of the physician to make sure the patient is as comfortable as possible, without providing medical assistance that the patient will use to end their life. *Id.* At such a late stage in the patient's medical journey, the physician's must tend to the patient to die peacefully, respecting the decision of the patient to end their life. *Id.*

[157] *See* Julian Savulescu, Editorial, *Conscientious Objection in Medicine*, 332 BRIT. MED. J. 294, 296 (2006) (discussing limitations on providers' rights).

> Certain constraints are necessary to ensure the legal, equitable, and efficient delivery of healthcare: Medical students and trainees must be aware of the commitments of the profession and be prepared to undertake these or not become doctors; the medical profession has an obligation to ensure that all patients are aware of the full range of services to which they are entitled; any would-be contentious objector must ensure that patients know about and receive care that they are entitled to from another professional in a timely manner that does not compromise their access to care; Doctors who compromise the delivery of medical services to patients on conscience grounds must be punished through removal of license to practice and other legal mechanisms; The place of expression and consideration of different values is at the level of policy relating to public medicine.

Id.; *see also* CODE OF ETHICS FOR NURSES § 5.2 (AM. NURSES ASS'N 2025) (providing standards required when providing care). Conscience-based objection is an important right to promote personal integrity but must be balanced with the patient's right to care and dignity. § 5.2.

abandon a suffering patient: "The duty to relieve pain and suffering is central to the physician's role as healer and is an obligation physicians have to their patients."[158] Providers are ethically and legally obliged to provide care to a suffering patient even if doing so violates their personal beliefs unless they assist the patient in transferring to a provider who will provide such proper care.[159]

The principle of "double effect" becomes relevant when assessing a provider's duty to provide care that violates their personal beliefs.[160] Dating to *Summa Theologica*, written by Thomas Aquinas in the thirteenth century, this principle states: "An action should only be performed if the intention is to bring about a good effect, and any bad effect that occurs as a consequence should be unintended or indirect and not occur before the good effect."[161] The following conditions must be met for the principle of double effect to apply: "the act itself is good or at least neutral; the good effect, not the bad effect, is what is intended; the good effect is not produced by the bad effect; there is a proportionately grave reason for permitting the bad effect."[162]

How does the principle of double effect apply in practice? Giving morphine to a dying patient who is in pain is a classic example of double effect.[163] The intended effect (to reduce pain) may lead to hastening death (an unintended possible effect which the

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Conscious-based refusals to participate exclude personal preference, prejudice, bias, convenience, or arbitrariness. *Id.*

[158] *See* UNIV. OF MINN. CTR. FOR BIOETHICS, *A Patient's Last Chapter: Ethical Considerations for VSED, Euthanasia, and MAID*, at 22:09 (YouTube, Aug. 28, 2024), https://www.youtube.com/watch (on file with the Suffolk University Law School Journal of Health and Biomedical Law) (reviewing ethics of suffering and palliation). "The duty to relieve pain and suffering is central to the physician's role as healer and is an obligation physicians have to their patients." *Id.*

[159] *See* Wechkin et al., *supra* note 7 (discussing how providers must distinguish beliefs from method of treatment).

[160] *See* E. Kendal, *How the Doctrine of Double Effect Rhetoric Harms Patients Seeking Voluntary Assisted Dying*, 21 BIOETHICAL INQUIRY 659, 660 (2024) (defining doctrine of double effect). The doctrine of double effect was first developed by Thomas Aquinas as an attempt to "delineate the conditions in which it is morally legitimate to cause or permit evil in the pursuit good." *Id.* at 660.

[161] *See* Thomas A. Cavanaugh, *Aquinas's Account of Double Effect*, 61 THOMIST 107, 111 (1997) (discussing origin and intention of doctrine of double effect); *see also Principle of double effect*, TAYLOR & FRANCIS, https://taylorandfrancis.com/knowledge/Medicine_and_healthcare/Medical_ethics/Principle_of_double_effect/ [https://perma.cc/3AH6-EW2U] (defining principle of double effect).

[162] *See* Kendal, *supra* note 159, at 660. There are four key factors in the doctrine of double effect that an action must satisfy to be considered acceptable:

> (1) The act when considered independent of its consequences must be of the sort that is morally permissible; (2) the intended outcome must be good, while the bad outcome can be foreseen but never intended; (3) the bad outcome must not be the method of obtaining the good outcome, i.e. it must not be the means of achieving the desired goal; (4) the benefit of the good outcome must reasonable outweigh the harm of the bad outcome.

Id.; *see also* Mary Katherine Brueck & Daniel P. Sulmasy**,** *The Rule of Double Effect: A Tool for Moral Deliberation in Practice and Policy*, HARV. MED. SCH. CTR. FOR BIOETHICS (Jan. 1, 2020), https://bioethics.hms.harvard.edu/journal/rule-double-effect [https://perma.cc/7D5V-RMVE] (discussing function of four conditions for double effect doctrine).

[163] *See id.* A common application of the double effect doctrine in medicine is in end-of-life care where high doses of morphine to relieve pain may also accelerate death. *Id.*

provider may personally oppose).[164] Yet, because the provider intends only the good effect (reduce pain), not possible hastening of death (the "bad" effect in the provider's view), the provider avoids the moral dilemma of providing care with which they disagree and which they do not intend. Similarly, when a provider prescribes medication to help make a ventilated patient comfortable (intended effect) when that patient has decided to discontinue the ventilation that is keeping them alive (an unintended effect which the provider may personally oppose), the provider avoids a personal moral dilemma of providing care with which they do not agree and which they do not intend.[165]

Following this logic, a health care professional will be deemed to behave ethically by providing comfort and care to a VSED patient (intended effect) without intending (or even approving of) the patient's decision to VSED. In this way, health care providers, while retaining their personal opposition to VSED, can adhere to their ethical duty not to abandonment a suffering patient. To do otherwise, as one ethicist states, would be "ethically incomprehensible."[166]

As noted by Paul T. Menzel, a bioethicist and a co-author of the widely regarded treatise on VSED:

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[164] *See id.*

> Applying the RDE, it is argued that the action of treating pain with morphine itself is good (or at least not objectionable), the relief of suffering, not death, is what is intended by the action of giving morphine, the possible death of the patient is not the means by which morphine achieves the good of relieving pain, and, given intense and severe pain and otherwise imminent death, there is a proportionately grave reason for permitting the risk of hastening death.

Id.

[165] *See generally* Paul S. Mueller, *Ethical and Legal Concerns Associated with Withdrawing Mechanical Circulatory Support: A U.S. Perspective*, 9 FRONTIERS CARDIOVASCULAR MED., July 26, 2022, at 1, 3 (looking to ethical permissibility of withholding treatment). Respect for patient wants and autonomy is the basis of informed consent and is optimized when the patient fully understands their treatment options. *Id.* The clinician must ensure that their patient fully understands their diagnoses and treatment options, even if it does not align with their personal beliefs. *Id.* Consistent with the double effect, clinicians should provide treatment to alleviate suffering even if the treatment may hasten death. *Id. See id.* at 2 (outlining principles of ethics regarding withholding and withdrawing life-sustaining treatments); *see also* Pierson, *supra* note 6, at 1 (discussing ethical scenario balancing patient and physician beliefs); Eva Elizabeth Bolt, H. Roeline Pasman & Bregje D Onwuteaka-Philipsen, *Patients Who Seek to Hasten Death by Voluntarily Stopping Eating and Drinking: A Qualitative Study*, 21 ANNALS FAM. MED., 534, 538 (2023) (explaining VSED considerations and expectations).

[166] *See* Brueck & Sulmasy, *supra* note 161 (describing double effect to justify actions like hastening death); *see also* Quill et al., *supra* note 31, at 71 (regarding elements of ethical prongs of VSED). As noted by Paul T. Menzel, a bioethicist and co-author of the widely regarding treatise on VSED:

> The ethical justification of palliative care for VSED is thus strong, a function…of three convincing points. First, the competent act of VSED is itself a morally protected liberty. Second, caregivers should respect that liberty even when they might think a particular patient should not exercise it. Third, when a patient does exercise it, caregivers should service their patients' best interest – that is, with palliative support.

Id.

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Given the above guidance on health care providers' ethical obligations to patients, how does Dr. X's conduct in the case of Mr. P measure up? Not well. While Dr. X was entitled to conscientiously object to providing medical care that violated Dr. X's personal beliefs, Dr. X was never called upon to provide medical care to Mr. P regarding Mr. P's Alzheimer's disease or Mr. P's VSED decision.[168] Mr. P's attending physicians monitored and managed his Alzheimer's care and VSED decision.[169] Thus, by inserting themself into the care of a patient being managed by other physicians and disregarding the treatment plan developed by the patient and those physicians, Dr. X violated the following principles of medical ethics:

- By substituting Dr. X's personal beliefs for those of a competent patient, Dr. X failed to provide care "with compassion and respect for human dignity and rights," and failed "to respect the rights of patients."[170]
- By intervening in the treatment plan developed by a patient and the patient's attending physicians (which Dr. X was not), Dr. X failed to "use the talents of other health professionals when indicated," to "regard responsibility to the patient as paramount," and to "be honest in all professional interactions."[171]
- By disregarding the treatment plan developed by a patient and the patient's treating physicians, without knowledge of, or any effort learn the facts of the patient's disease or medical care, and without notifying or consulting either the patient or the treating physicians, Dr. X failed to "make relevant information available to…[a] patient[]," and failed to "use the talents of other health professionals when indicated."[172]

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[167] *See* Quill et al., *supra* note 31, at 71 (regarding elements of ethical prongs of VSED).

[168] *See* Pierson, *supra* note 6, at 2 (demonstrating implications of VSED decisions). Mr. P met with Dr. X as requested by his hospice care. *Id.* He informed Dr. X that he met with his Alzheimer's physicians and that because of the rapid progression in his Alzheimer's disease and the need for him to act while he was still cognitively capable, if he wanted to begin VSED he would have to do so in the next week. *Id.* Dr. X said, "No. I will not allow this. This is suicide. This is wrong . . . your life has value. So, no. I will not allow this." *Id.*

[169] *See id.* at 1 (furthering hypothetical scenario). Mr. P only saw Dr. X for minor ailments and routine checkups, and he never once discussed his Alzheimer's with Dr. X. *Id.* Alzheimer's specialists from a nearby academic medical center handled all of Mr. P's Alzheimer's care, including examinations, assessments, evaluations, and prescribing medications and treatments. *Id.*

[170] *See id.* at 2; *see also* AM. MED. ASS'N, *supra* note 151 (outlining ethical standards for practicing physicians). Principle II of the American Medical Associations Principles of Medical Ethics states to "be honest in all professional interactions." AM. MED. ASS'N , *supra* note 151.

[171] *See* Pierson, *supra* note 6, at 2 (discussing hypothetical VSED scenario); AM. MED. ASS'N, *supra* note 151 (standardizing physician honorable behavior). Principle V outlines how physicians should use and rely on the talents and knowledge of other physicians when indicated. AM. MED. ASS'N, *supra* note 151. Similarly, a physician should treat their responsibility to the patient with the upmost respect and while upholding the standards of professionalism, be honest in their interactions. *Id.*

[172] *See* AM. MED. ASS'N, *supra* note 151 (listing principles adopted by American Medical Association). "A physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, make relevant information available to patients,

- In representing to a patient that Dr. X would follow the patient's advance directive and then refusing to do so, Dr. X violated Principles of Medical Ethics as well as state law.[173]

Turning next to the hospices' conduct in the hypothetical, there are two questions: Did the hospice that accepted Mr. P but withdrew its admission upon receiving Dr. X's call comply with ethical standards when it rescinded its admission decision? Did the two subsequent hospices that refused to admit Mr. P to services when Mr. P qualified for admission comply with medical ethics? The answer to both questions is no.

The prevailing standard of care in the United States that hospice providers admit patients pursuing VSED by the second or third day of the VSED process.[174] By their conduct, the three hospices failed to comply with this standard of care for VSED patients.[175] In so doing, these hospices abandoned a suffering patient who qualified for hospice, apparently solely because the patient chose VSED.[176] This fails to comply with the *Clinical Guidelines for VSED* for when hospice care is appropriate, [177] as well as best practices for developing and following internal protocols regarding VSED patients.[178]

State laws on medical malpractice embed these ethical and legal requirements into health care providers' legal and professional responsibilities as licensed health care

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colleagues, and the public, obtain consultation, and use talents of other health professionals when indicated." *Id.*; Pierson, *supra* note 6, at 2 (outlining hypothetical medical situation).

[173] *See* ALA. CODE § 22-8A-8 (2025) (codifying procedures for when physician refuses compliance with patient's advance directive). A physician who refuses to follow a patient's advance directive shall "promptly so advise the declarant" and "shall reasonably cooperate to assist the declarant, . . . in the timely transfer . . . to another health care provider that will follow the directions." *Id.*; *see also* Dan W. Brock, *Conscientious Refusal by Physicians and Pharmacists: Who Is Obligated to Do What, and Why?*, 29 THEORETICAL MED. BIOETHICS 187, 188 (2008) (discussing healthcare providers refusing to fill legal prescriptions).

[174] *See* Pamela Bucy Pierson, *Hospice Admissions Standards: It's Time They Were Updated to Reflect the Reality of Alzheimer's Disease*, 29 QUINNIPIAC HEALTH L. J. (forthcoming 2026) (discussing results of systematic review of four decades of academic publications on VSED).

[175] *See id.*; *see also* Quill et al., *supra* note 31, at 71 (discussing ethical elements of VSED); UNIV. OF MINN. CTR. FOR BIOETHICS, *supra* note 157, at 22:20 (citing AMA Code of Medical Ethics Opinion 5.6). Speaker Joel Wu looks towards the ethics of suffering and palliation, specifically with treatment options that may hasten death at the end of a patient's life. UNIV. OF MINN. CTR. FOR BIOETHICS, *supra* note 157.

[176] *See* Pierson, *supra* note 6, at 3 (showing severe dehydration, immobility, and labored breathing, yet denying hospice solely for VSED). Although Mr. P showed clear signs of advanced physical decline and met the clinical criteria for hospice care, the hospice nurse denied him admission solely because he was engaging in voluntary stopping of eating and drinking, exposing a gap between medical eligibility and hospice polices that respects patient autonomy at the end of life. *Id.* at 3.

[177] *See id.* at 3 (documenting repeated refusals, admitting only after day nine, leading to terminal agitation and death); *see also* Wechkin et al., *supra* note 7, at 628-29 (outlining key considerations and steps to initiate and support patient's VSED decision). The guidance emphasizes that patients and clinicians must carefully evaluate timing, cognitive capacity, and logistical preparation, including hospice coordination and caregiving support before initiating VSED to ensure a dignified and supported end of life process. Wechkin et al., *supra* note 7.

[178] *See Gruenewald, Long-Term Care Facilities*, *supra* note 37, at 1216-17 (providing safeguards and guidance to protect patients at end of life). These practice recommendations require clinicians to implement safeguards that prevent errors, abuse, and coercion while addressing intractable end of life suffering, balancing patient relief with non-abandonment obligations. *Id.*; Quill et al., *supra* note 31, at 128 (describing VSED legally permissible). VSED offers patients a legally permitted and compassionate means to hasten death respecting autonomy and choice while requiring careful clinician and caregiver support. Quill et al., *supra* note 31.

professionals.[179] Health care providers are deemed to be negligent and thus liable for medical malpractice if they fail to exercise "the care, skill, and knowledge regarded as competent among similar medical providers in the same or similar circumstances."[180] The relevant standard of care, skill, and knowledge is a national standard to which all health care providers must adhere.[181]

In 2024, the American Law Institute revised the *Restatement (Third) of Torts — Medical Malpractice* and made clear that clinical guidelines are relevant in determining what constitutes competent care.[182] The *Clinical Guidelines on VSED* are uniformly adopted standards for VSED best practices. Notably, these are the only standards for VSED, which makes them especially compelling since, unlike other medical areas where there competing guidelines and recommendations, the C*linical Guidelines for VSED* are the recognized authority.[183] The authority of these *Guidelines* is further enhanced by their alignment with recognized clinical best practices and established law that VSED is the right of every competent adult.[184]

The *Clinical Guidelines on VSED* as well as accepted best practices make clear raised serious questions whether Dr. X, the three hospices at issue, or any health care provider behaving similarly has provided the "care, skill, and knowledge regarded as

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[179] *See* B. Sonny Bal, *An Introduction to Medical Malpractice in the United States*, 467 CLINICAL ORTHOPEDICS & RELATED RSCH. 339, 340 (2009) (explaining state laws create differing legal duties and protections); Joseph S. Kass & Rachel V. Rose, *Medical Malpractice Reform: Historical Approaches, Alternative Models, and Communication and Resolution Programs*, 18 AM. MED. ASS'N J. ETHICS. 299, 305-06 (2016) (showing state laws affect communication, and resolution programs adaptation, and physical disclosure).

[180] *See* Larry S. Stewart & Robert S. Peck, *A Bridge Too Far: Practice Guidelines in the New ALI Medical Malpractice Statement*, 51 AM. J.L. & MED. 1, 4-5 (2025); Heather Morton, *Medical Liability/Malpractice Merit Affidavits and Expert Witness*, NAT'L CONF. OF STATE LEGISLATURES (Aug. 11, 2021), https://www.ncsl.org/financial-services/medical-liability-malpractice-merit-affidavits-and-expert-witnesses [https://perma.cc/6PJL-CWJL] (summarizing state requirements for medical malpractice claims).

[181] *See* Morton, *supra* note 179; Kass & Rose, supra note 178, at 301 (summarizing National Conference of State Legislatures' analysis of medical malpractice guidelines); *see also* Donna Vanderpool, *The Standard of Care*, 18 INNOVATIONS CLINICAL NEUROSCIENCE 50, 50 (2021) (defining legal standard of care).

[182] *See* Daniel G. Aaron et al., *A New Legal Standard for Medical Malpractice*, 33 JAMA 1161, 1161 (2025) (stating American Law Institute revised standard for medical malpractice). The American Law Institute's revised standard directs courts to evaluate medical negligence using a more patient-centered, evidence-based approach, allowing juries to reject customary practices that fail to meet contemporary standards while still considering prevailing medical norms. *Id.*; *see also* Kerri Miller, *New Medical Malpractice Rules Issued by American Law Institute,* CONEXIANT (Feb. 26, 2025), https://conexiant.com/internal-medicine/articles/med-mal-rules-change/ [https://perma.cc/WL32-U2PW] (explaining revised malpractice standards). The American Law Institute's Restatement (Third) of Torts redefines the standard of care by prioritizing evidence-based medicine and a reasonable framework, allowing courts to move beyond strict adherence to customary practice while promoting patient safety and modernizing malpractice principles. Miller, *supra*.

[183] *See* Wechkin et al., *supra* note 7, at 625-26 (providing practical recommendations for VSED for clinicians); *see also* Aaron et al., *supra* note 181, at 1161 (stating inconsistencies among guidelines); Wechkin et al., *supra* note 7, at 630-31 (providing recommendations to navigate VSED guidelines); Vanderpool, *supra* note 180, at 50 (defining legal standard of care).

[184] *See* Wechkin et al., *supra* note 7, at 626; *see also Voluntarily Stopping Eating and Drinking (VSED)*, END OF LEAVELIFE CHOICES N.Y., https://endoflifechoicesny.org/vsed-voluntarily-stopping-eating-drinking/ [https://perma.cc/K3R4-NYYN] (explaining VSED and challenges).

competent among similar medical providers in the same or similar circumstances."[185]

VI. Part Five: Society's Ethics

This section addresses two questions concerning society's ethical obligation to individuals with dementia who choose VSED: Does society have a *right* to stop individuals from choosing VSED? Does society have an *obligation* to provide care and support to individuals who choose VSED? In the words of John Stuart Mill: "Where does the authority of society begin and where does it end?"[186]

A. Does Society Have the Right to Stop Individuals From Choosing VSED?

The lodestar in answering this question is Immanuel Kant's and John Stuart Mill's writings on personal autonomy and justice.[187] In free societies, we allow competent adults to choose their jobs and careers, to live where they wish to live, to love whom they love, to spend their free time as they choose, to believe in what they believe, to follow the media they prefer. We allow competent adults who are suffering from terminal diseases to decide whether to stop dialysis, disconnect ventilators, remove nutrition tubes, forgo curative treatment, or enter hospice. Given this, does society have the right to tell a competent adult who has lived a full life that he or she does not have the right to pursue the only lawful end-of-life option available to them for avoiding the long, lingering, debilitating, agonizing death dementia will otherwise bring?

The answer is no. There is no rational basis to deny competent adults this right. There is no doubt that a just society has the right, indeed the moral obligation, to protect vulnerable individuals who do not have the cognitive capacity to make informed decisions or who are under the influence of a physical or mental illness, from making a rash end-of-life decision. But that is not what is at issue. Governed by the *Clinical*

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[185] *See* Larry S. Stewart & Robert S. Peck, *A Bridge Too Far: Practice Guidelines in the New ALI Medical Malpractice Statement*, 51 AM. J.L. & MED. 1, 4-5 (2025); Heather Morton, *Medical Liability/Malpractice Merit Affidavits and Expert Witness*, NAT'L CONF. OF STATE LEGISLATURES (Aug. 11, 2021), https://www.ncsl.org/financial-services/medical-liability-malpractice-merit-affidavits-and-expert-witnesses [https://perma.cc/6PJL-CWJL] (summarizing state requirements for medical malpractice claims).

[186] *See Voluntary Stopping of Eating and Drinking (VSED)*, VT. ETHICS NETWORK, https://vtethicsnetwork.org/medical-ethics/voluntarily-stopping-eating-and-drinking [https://perma.cc/86XZ-2C97] (discussing ethics of VSED). Some argue VSED violates the sanctity of life, while other recognize it as a patient's right to refuse unwanted medical treatment. *Id.* Unlike other methods, VSED lets patients control the process without physician involvement and gives them time to consider options, which provides ethical and practical advantages. *Id.*; *see also* Mill, *supra* note 59, at 140 (discussing ethics and limits of authority over individuals). Stating individual rights are not innate but emerge through social development, and therefore individual liberty is limited by authority and interest of society. Mill, *supra* note 59, at 40; Bryan A. Liang & Laura Lin, *Bouvia v. Superior Court: Quality of Life Matters*, 7 AM. MED. ASS'N J. ETHICS 177, 177 (2005) (explaining lawsuit for right to refuse medical treatment). Despite plaintiff's protests, the hospital acted to prevent starvation, as she could survive many years with adequate nutrition. Liang & Lin, *supra*. Bouvia sued the hospital, seeking court order to remove the feeding tube and honor her refusal of medical treatment. *Id.*

[187] *See* Mill, *supra* note 59, at 140 (discussing scope of society's authority over individual rights); *see also* Mclean, *supra* note 57 (discussing Kant's and Mill's views on autonomy and individual liberty).

Guidelines for VSED and clinical best practices, VSED has safeguards that protect against this risk.[188]

The pre-VSED safeguards of competency, voluntariness, and presence of suffering align with the normative ethics of John Stuart Mill. As noted, Mill counsels that for practical as well as ethical reasons, society has limited moral authority to overrule an individual's judgment about matters that impact only that individual.[189] As Mill states, society looks at a situation "merely from without and cannot see circumstances from the perspective of a person experiencing any situation."[190] Accordingly, society may be entirely mistaken or may misapply its general assumptions to individual circumstances.[191] This is why competent adults are entitled to decide what goes into their bodies, and what does not.

B. Does Society Have an Obligation to Support Individuals Who Choose VSED?

Does society have an ethical obligation to support individuals with dementia who seek VSED? If so, how? This Article argues that in two ways, all of us, whatever our views about end-of-life decisions, have the ethical duty to support individuals with dementia who choose VSED. The first duty is to inform ourselves about the reality facing these individuals. The second duty is to treat these individuals with empathy.

i. Duty to Inform

To inform ourselves about the reality facing those with dementia who choose VSED, we need to be informed about what living and dying with dementia is like, what the available end-of-life options are, and what the options entail. It should not be difficult to inform ourselves about these topics.

Turning first to the topic of Alzheimer's and dementia, there is a plethora of readily available information. Major news outlets publish a "high and consistent" number of articles on Alzheimer's and dementia.[192] Approximately 350 dementia research articles are published w*eekly*, 266,000 posts on dementia are shared monthly on X (formerly Twitter), thousands of posts and dedicated newsletters on dementia appear

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[188] *See* Wechkin et al., *supra* note 7 (discussing clinical guidelines for VSED); *see also Frequently Asked Questions about Voluntarily Stopping Eating and Drinking (VSED)*, COMPASSION & CHOICES (July 20, 2022), https://compassionandchoices.org/wp-content/uploads/2024/03/FAQs-VSED.pdf [https://perma.cc/B3VR-M2BE] [hereinafter *VSED FAQs*] (explaining individuals who may opt for VSED). Only mentally capable individuals can opt for VSED, a constitutionally protected right. *VSED* FAQs, *supra*. The laws that govern the withdrawal of food and drinks for a person who is not mentally capable can vary by state. *Id.*

[189] *See* Pierson, *supra* note 6, at 1 (creating hypothetical); *see also* Mill, *supra* note 59, at 143-44 (discussing society's duty to one another). Mill states that society looks at a situation "merely from without" and cannot see circumstances from the perspective of a person experiencing any situation. *Id.* at 144. As such, society could well be "altogether wrong" or misapply its presumptions to individual cases. *Id.* at 143-44.

[190] *See* MILL, *supra* note 59, at 143-44 (distinguishing collective societal perception versus individual experience). Society's interference in overruling an individual's judgment in matters that concern only that person must rest on general assumptions, which may be entirely mistaken. *Id.* Even when accurate, they are just as likely to be misapplied to particular cases by those no more familiar with the circumstances than outside observers. *Id.*

[191] *See id.* (discussing societies incorrect presumptions).

[192] *See* Atiqur Sm-Rahman, Chih Hung Lo, & Yasmin Jahan, *Dementia in Media Coverage: A Comparative Analysis of Two Online Newspapers Across Time*, 18 INT'L J. ENV'T RSCH. & PUB. HEALTH, Oct. 5, 2021, at 1, 3-4 (discussing publications on Alzheimer's and dementia patients). The media portrayal of dementia is consistent, but there is an established association between this coverage and the social perceptions of dementia. *Id.*

on Substack, the #Dementia hashtag on TikTok has over 3.2 billion views.[193] There are scores of books and journal articles, both in the academic and popular press.[194]

This widespread coverage reflects the reality that Alzheimer's and other dementia diseases are impacting millions of people. All we have to do is look around us to see how dementia affects real people in real ways. It is our families, neighbors, friends, and colleagues who are impacted by Alzheimer's and related dementia diseases. Over 7 million Americans have Alzheimer's or another dementia; over 12 million Americans provide care to family members with dementia.[195] The Alzheimer's impact on these individuals ripples throughout society. Most caregivers of those with dementia are middle-aged (53% are aged 45-64 years old).[196] They are the sandwich generation, caring for their children and an older person, while trying to make a living.[197] Their burden is heavy: They put in an average of 31 hours per week of caregiving; most (52%) do so for 5 years or more.[198]

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[193] *See* Sarah Louadi et al., *Podcasts as Open-Access Knowledge Dissemination Tools for Researchers: Lessons from Three Years of AMiNDR Podcast*s *(A Month in Neurodegenerative Disease Research)*, 19 ALZHEIMER'S & DEMENTIA, Dec. 25, 2023, at 1, 1 (discussing data of articles posted on dementia); *see also* Juanita-Dawne Bacsu et al., *Stigma of Dementia on Social Media During World Alzheimer's Awareness Month: Thematic Analysis of Posts*, 9 J. MED. INTERNAT RSCH. FORMATIVE RSCH., June 2, 2205, at 1, 2 (discussing tweets published on X during Alzheimer's awareness month); Evan H. Farr, *TikTok and Caregiving*: *The #Dementia Hashtag on TikTok Has over 3 Billion Views!*, FARR. L. FIRM: EVERYTHING ELDER L. (Nov. 8, 2022), https://www.farrlawfirm.com/tiktok-and-caregiving-the-dementia-hashtag-on-tiktok-has-over-3-billion-views [https://perma.cc/KGV4-LUNA] (discussing TikToks published with hashtag dementia). *See, e.g.*, Bob Koszkalda, *The Alzheimer's Hub of Hope*, SUBSTACK, https://thealzheimershubofhope.substack.com/ [https://perma.cc/8PZ8-EAW8] (providing Alzheimer's article hub); Annie Fenn, *Brain Health Kitchen*, SUBSTACK, https://brainhealthkitchen.substack.com/ [https://perma.cc/79SW-E72S] (offering Substack discussing food and brain health); Louisa Nicola, *Neuro Athletics*, SUBSTACK, https://neuroathletics.substack.com [https://perma.cc/ZWE9-SCUF] (offering newsletter neuroscience research); Courtney Martin, *The Examined Family*, SUBSTACK, https://courtney.substack.com/ [https://perma.cc/S3JP-UQBN] (sourcing newsletters about living in complicated world and experiences family members with dementia); Beverly Thorn, *Before I Lose My Own Mind*, SUBSTACK, https://beverlythorn.substack.com/ [https://perma.cc/F3BZ-HTP9] (discussing challenges caring for and losing loved ones with dementia).

[194] *See, e.g.*, Quill et al., *supra* note 31 (discussing VSED option for seriously ill patients); PHYLLIS SCHACTER, CHOOSING TO DIE: A PERSONAL STORY 44 (2017) (offering memoir and guidebook from experience with husband and his VSED); Lewis Cohen, Winters End: Dementia and Dying Well (2024) (discussing account of Alzheimer's patient's VSED experience).

[195] *See* Amanda Brahlek, *Alzheimer's and Related Dementias*, AM. ASS'N FOR GERIATRIC PSYCHIATRY (Oct. 15, 2025), https://aagponline.org/patient-article/alzheimers-and-related-dementias/ [https://perma.cc/SCH4-WXHM] (discussing statistics of Americans affected by dementia and Alzheimer's); *see also* 2025 ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 3 (discussing statistics of affected Americans).

[196] *See* Alzheimer's Ass'n, *supra* note 3, at 51-52 (discussing age of caregivers to Alzheimer's patients). Most of these caregivers are middle-aged, with 53% being aged forty-five to sixty-four. *Id.* They are the sandwich generation, caring for their children and an older person, putting in an average of thirty-one hours per week, with most doing so for 5 years or more. *Id.*

[197] *See id.* (discussing data of ages carrying for older person).

[198] *See id.* at 53 53(discussing hours of caregiving given per week).

Information about end-of-life options is also widely available to the public.[199] Whereas "[t]he topic of death and dying had in the not too distant past been seen as taboo…willingness and need to talk openly about it appears to be on the increase."[200] Over the past thirty years, the passage of Medical Aid in Dying (MAID) laws in thirteen states and the District of Columbia has generated significant public dialogue about end-of-life options in a world where death is increasingly controlled by the medical system.[201]

For real-world information about end-of-life options and why and whether to consider them, we can, as with the topic of dementia, turn to the people around us who are dealing with these decisions. As noted in a recent Pew Study:

> Many Americans have faced end-of-life medical issues through experiences with friends or relatives. About half of adults (47%) say they have a friend or relative who has had a terminal illness or who has been in a coma within the last five years. About half of these adults (23% of the general public) report that the issue of withholding life-sustaining treatment arose for their loved one." [202]

In short, there is readily available, accessible information available to all of us on the topics of Alzheimer's and related dementia, and on end-of-life decisions. However, most of us are quite adept at avoiding thinking about these topics. Although more than

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[199] *See Different Care Settings at the End of Life*, NAT'L INST. ON AGING, NAT'L INST. OF HEALTH (Jan. 31, 2022), https://www.nia.nih.gov/health/end-life/different-care-settings-end-life [https://perma.cc/9CNL-8DLW] (highlighting end-of-life care examples); *Making Decisions for Someone at the End of Life*, NAT'L INST. ON AGING, NAT'L INST. OF HEALTH (Nov. 17, 2022), https://www.nia.nih.gov/health/end-life/making-decisions-someone-end-life [https://perma.cc/4QRM-8SJQ] (examining end-of-life decision making strategies); *Providing Care and Comfort at the End of Life,* NAT'L INST. ON AGING, NAT'L INST. OF HEALTH (Nov. 17, 2022), https://www.nia.nih.gov/health/end-life/providing-care-and-comfort-end-life [https://perma.cc/SGS8-RP4W] (describing end-of-life common needs plus bodily changes).

[200] *See* Mark Taubert et al., *Palliative Social Media*, 4 Brit. MED. J. SUPPORT PALLIATIVE CARE 13, 13-16 (2014). Conversations about death, illness, and dying are now increasingly happening in public online spaces, especially on platforms like Facebook, Twitter, and YouTube. *Id.* at 13. Social media is "alive with discussions, comments and anecdotes" about these subjects, showing that people are no longer keeping end-of-life issues entirely private or unspoken. *Id.* This shift to broader public-awareness campaigns encourage society to become more prepared for death and dying. *Id.* at 16.

[201] *See, e.g.*, Brittany Maynard, *My right to death with dignity at 29*, CNN (Nov. 2, 2014), https://edition.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity [https://perma.cc/V29D-QD2P]; Sarah Wildman, *If My Dying Daughter Could Face Her Mortality, Why Couldn't the Rest of Us?*, N.Y. TIMES (Nov. 25, 2024), https://www.nytimes.com/2024/11/25/opinion/children-cancer-grief.html [https://perma.cc/7EXD-QSBU]; Stephanie Nolen, *A Cancer Patient Chose Assisted Death. That Wasn't the Last Hard Choice.*, N.Y. TIMES (Aug. 3, 2025), https://www.nytimes.com/2025/08/03/health/maid-medical-assistance-dying-colombia.html [https://perma.cc/4QEK-R6FZ]; JoNel Aleccia, *This Couple Died By Assisted Suicide Together. Here's Their Story*, TIME (Mar. 6, 2018), https://time.com/5179977/assisted-suicide-couple-death/ [https://perma.cc/JT3C-74EK]; *Rosemary Bowen's Story*, END OF LIFE CHOICES N.Y. (May 25, 2025), https://endoflifechoicesny.org/rosemary-bowens-story/ [https://perma.cc/XZL9-N9XL].

[202] *See Views on End-of-Life Medical Treatments*, PEW RSCH. CTR. (Nov. 21, 2013), https://www.pewresearch.org/religion/2013/11/21/views-on-end-of-life-medical-treatments/ [https://perma.cc/E9D2-M5F2] (reporting 23% of adults said withholding life-sustaining treatment arose for loved one).

two-thirds of Americans (68%) say it is important to discuss end-of-life preparations with loved ones, fewer than half (47%) have had those discussions.[203] Just over one-third (36.7%) of Americans have an advance directive.[204]

But such avoidance, this Article suggests, is immoral. This is true for two reasons. The first reason is what avoidance does to others. Failing to inform ourselves about diseases that terrify us, but which others face, leaves all alone those who are living with these diseases and the choices they present. Our lack of information about these diseases and those who have them means we are more likely to judge and condemn rather than to show compassion; more likely to act based upon misconceptions rather than upon facts; more likely to pursue ill-informed social policies rather than policies of wisdom and grace.

The second reason ignoring these issues is immoral is that doing so hurts us as individuals. We are worthy of self-care. Being ill-informed about diseases one-third of us are likely to develop leaves us more vulnerable to developing these diseases and dealing effectively with them. Most of us are uninformed. To take one example, a 2025 survey from Alzheimer's International found that over 70% of people mistakenly believe dementia is a normal part of aging rather than a neurodegenerative disorder.[205]

Our lack of information and avoidance means we do not learn about the behaviors we can adopt that prevent and delay our chances of developing Alzheimer's or related dementia.[206] It means we are more likely to suffer from a delayed dementia

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[203] *See Americans think about death, but won't plan for it*, Insurance News Net (Sep. 1, 2022), https://insurancenewsnet.com/innarticle/americans-think-about-death-but-wont-plan-for-it [https://perma.cc/3329-LG9Y]. Many Americans recognize the importance of end-of-life conversations but still fail to have them. *Id.* While more than two-thirds view these discussions as important, fewer than half have actually talked with loved ones about their wishes. *Id.* This contrast suggests that awareness alone does not necessarily lead to preparation. *Id.*

[204] *See* Kuldeep N. Yadav et al., Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care, 36 Health Affs. 1244, 1244 (2017).

[205] *See* Bacsu et al., *supra* note 192, at 2 (reporting over 70% of respondents mistakenly viewed dementia normal aging, not neurodegeneration).

[206] *See Cognitive Health and Older Adults*, Nat'l Inst. on Aging, Nat'l Inst. of Health (June 11, 2024), https://www.nia.nih.gov/health/brain-health/cognitive-health-and-older-adults [https://perma.cc/29PC-VDT4]. Many lifestyle and environmental factors affecting cognitive health "can be changed or managed." *Id.* Scientific research suggests there are concrete steps people can take to reduce the risk of cognitive decline and maintain cognitive health over time. *Id.* Examples of those behaviors include managing blood pressure, eating a healthy diet, staying physically active, keeping the mind engaged, and maintaining social connections. *Id.*; *Preventing Alzheimer's Disease: What Do We Know?*, Nat'l Inst. on Aging, Nat'l Inst. of Health (Oct. 10, 2023), https://www.nia.nih.gov/health/alzheimers-and-dementia/preventing-alzheimers-disease-what-do-we-know [https://perma.cc/Z9T3-U94Q] [hereinafter *Preventing Alzheimer's Disease*]. Researchers have identified several promising interventions that may help prevent, delay, or slow Alzheimer's disease and related cognitive decline. *Preventing Alzheimer's Disease*, *supra*. Managing blood pressure, increasing physical activity, and cognitive training are supported by encouraging evidence. *Id.* Healthy dietary choices and social connection may help reduce dementia risk. *Id.*

diagnosis, and internalize the stigma that arises from misinformation.[207] It means we become victims of dementia instead of power over it.

Being ill-informed about our end-of-life options means that whenever our time to die draws near, we are more likely to have a "bad death" instead of a "good death" and we are unable to help prepare those we leave behind. As Julie McFadden, hospice nurse and author of *Nothing to Fear: Demystifying Death to Live More Fully*, write: "The only way to have a good death instead of a bad death is to prepare for it, especially in our age of medically managed deaths."[208] In short, informing ourselves about Alzheimer's, dementia, and end-of-life decisions is our ethical duty as members of society – both for the sake of others, and for ourselves.

ii. Duty to Show Empathy

The second way we can behave ethically toward those who have dementia and choose VSED is to treat these individuals with empathy. Empathy is "the ability to sense other people's emotions, coupled with the ability to imagine what someone else might be thinking or feeling."[209]

In one sense, it should not be difficult for us to be empathetic since biologically, we are programmed to be so.[210] The ethics of ancient Greece as well as modern day evolutionary biology and behavioral science speak to this.[211]

The early study of ethics arose from the belief that ethics is important for the survival of a society.[212] Greek mythology recounts that the god Zeus pitied humans who were physically inferior to other creatures.[213] To compensate for humans' limitations, Zeus endowed people with empathy, compassion, and a sense of justice, enabling them to form cooperative societies whose collective strength surpassed that of other

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[207] *See Over 41 Million Cases of Dementia Go Undiagnosed Across the Globe – World Alzheimer Report Reveals*, ALZHEIMER'S DISEASE INT'L (Sep. 21, 2021), https://www.alzint.org/news-events/news/over-41-million-cases-of-dementia-go-undiagnosed-across-the-globe-world-alzheimer-report [https://perma.cc/SB99-7FMC]. Delayed dementia diagnosis is a widespread problem. *Id.* 75% of dementia cases worldwide go undiagnosed, and that figure rises as high as 90% in lower- to middle-income countries. *Id.* The stigma remains a major barrier to diagnosis, including among clinicians, and that "lack of awareness and stigma within healthcare systems" has contributed to "alarmingly low diagnosis rates." *Id.*; Bacsu et al., *supra* note 192 (explaining dementia-related stigma causes discrimination and social exclusion and contributes to delayed diagnosis).

[208] *See* JULIE MCFADDEN, NOTHING TO FEAR: DEMYSTIFYING DEATH TO LIVE MORE FULLY, (2024) (discussing end-of-life journey from hospice nurse perspective).

[209] *See What Is Empathy?,* UNIV. OF BERKELEY: GREATER GOOD MAGAZINE, https://greatergood.berkeley.edu/topic/empathy/definition [https://perma.cc/ZF36-4AX5]. Empathy involves both emotional awareness and perspective-taking. *Id.* Empathy is the ability to recognize another person's emotions while also imagining what that person may be thinking or feeling. *Id.* Researchers distinguish between "affective empathy," which involves sharing or responding to another person's emotions, and "cognitive empathy," which involves understanding those emotions. *Id.*

[210] *See id.* Empathy has been deeply rooted and observed in our society since the beginning of time. *Id.* It is also not just something seen in humans; it has been demonstrated in our primate relatives and even in our domestic animals, such as dogs. *Id.*

[211] *See* Helen Riess, *The Science of Empathy*, 4 J. PATIENT EXPERIENCE 74, 75-76 (2017). *See generally* ARTHUR BERNARD COOK, ZEUS: A STUDY IN ANCIENT RELIGION (Cambridge Univ. Press 1940) (documenting Zeus's Greek ideations).

[212] *See* Peter Singer, *Ethics*, BRITANNICA (Mar. 20, 2026), https://www.britannica.com/topic/ethics-philosophy [https://perma.cc/9Z63-ZPCE] (discussing origin of ethics).

[213] *See id.* (explaining Plato's accounts of Zeus).

animals.[214] Zeus must have known a thing or two. Studies by modern-day evolutionary biologists show that ethical behavior towards others has an evolutionary advantage because societies in which individuals are collaborative survive better and longer than societies where individuals are not collaborative.[215]

Behavioral science shows another advantage of treating others with empathy, and kindness -- doing so is good for those who demonstrate such traits.[216] Studies indicate that empathy is connected to humans achieving true happiness.[217] Individuals who are empathetic, compassionate, and altruistic have greater resilience, more positive mental health and well-being, better life adjustment, and less hopelessness and depression.[218]

Studies of medical students provide an interesting case study on empathy.[219] In particular, these studies show that medical students' empathy declines during medical training and the impact of this decline.[220]

Patients are impacted by physicians' lack of empathy:: "Uncompassionate care and treatment devoid of empathy results in dissatisfied patients who are unlikely to follow through with treatment recommendations, resulting in poorer health outcomes and damaged trust in health provider relationships."[221] The vitality of the medical

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[214] *See id.* (expanding on Plato's account of Zeus's idea of morality).

[215] *See* CHARLES DARWIN, THE DESCENT OF MAN AND SELECTION IN RELATION TO SEX 88, 106 (Princeton Univ. Press 1981); *see also* Riess*, supra* note 210, at 76 (discussing ethical behaviors in certain societies).

[216] *See* DANIEL GOLEMAN, EMOTIONAL INTELLIGENCE: WHY IT CAN MATTER MORE THAN IQ 96-97 (Bantam Books 1995) (discussing behavioral research showing empathy factor for success). The benefits of being empathetic begin early: "Children…who showed an aptitude for reading feelings nonverbally were among the most popular in their schools, [and] the most emotionally stable. They also did better in school, even though, on average, their IQs were not higher than those of children who were less skilled at reading nonverbal messages." *Id.*

[217] *See* MARTIN E. P. SELIGMAN, AUTHENTIC HAPPINESS: USING THE NEW POSITIVE PSYCHOLOGY TO REALIZE YOUR POTENTIAL FOR LASTING FULFILLMENT 54 (The Free Press 2002) (discussing correlation between empathy and happiness).

[218] *See id.* at 54; *see also* The Oxford Handbook of Plato (Gail Fine ed., 2d ed. Oxford Univ. Press 2019) (analyzing Plato's philosophy); STEVEN M. SOUTHWICK & DENNIS S. CHARNEY, RESILIENCE: THE SCIENCE OF MASTERING LIFE'S GREATEST CHALLENGES 24 (3d. ed. Cambridge Univ. Press 2023) (discussing scientific research regarding emotional and mental resilience).

[219] *See* Mohammadreza Hojat et al., *The Devil is in the Third Year: A Longitudinal Study of Erosion of Empathy in Medical School*, 84 ACAD. MED. 1182, 1182 (2009) (highlighting decrease in empathy among medical students); *see also* Paula Nunes et al., *A Study of Empathy Decline in Students from Five Health Disciplines During Their First Year of Training,* 2 INT'L J. MED. EDUC. 12, 12 (2011) (analyzing empathy levels of students in health sciences).

[220] *See* Riess, *supra* note 210, at 74 (analyzing impact of decreased empathy in medical field). Over the course of medical training, students experience a decrease in empathy that can have damaging effects on patients and providers including poor health outcomes and reduced patient trust in healthcare providers. *Id.* at 74; *see also* Hojat et al., *supra* note 218 (discussing lack of empathy training). Despite the general understanding that effective medical providers must be empathetic, the field lacks a consistent measure of empathy. Hojat et al., *supra* note 218, at 1182. Without this, it is challenging for medical schools to effectively incorporate empathy training into academic curriculum. *Id.*; Nunes, *supra* note 218 (offering further data). Students in various health sciences disciplines including dentistry, pharmacy, and nursing also experience a decrease in empathy during their first year of training. Nunes, *supra* note 218, at 12.

[221] *See* Riess, *supra* note 210 (offering tangible impact of lack of empathy). When a patient feels their providers lack empathy, general satisfaction with that provider and the healthcare system as a whole is common. *Id.* at 74. Additionally, when a patient lacks trust in their provider, they are less likely to adhere to their treatment and may experience adverse health outcomes. *Id.*

profession as a whole is impacted by physicians' decline in empathy. As Helen Riess, MD, Professor of Psychiatry at Harvard Medical School, who conducts research on improving empathy and relational skills in physicians, writes: "[Empathic medical care is associated with many benefits including improved patient experiences, adherence to treatment recommendations, better clinical outcomes, fewer medical errors and malpractice claims, and higher physician retention."[222] In other words, empathic and compassionate care is also cost-efficient care.

Physicians themselves are impacted as their empathy for patients declines. Physicians who measure low in empathy in medical training have a higher incidence of physician burnout and distress.[223] Providers who demonstrate empathy face fewer malpractice claims, experience lower levels of burnout, and contribute to greater societal trust and satisfaction with the healthcare system.

To develop empathy towards those suffering from disease at the end of their life who choose VSED, we can turn to their personal stories. For example, a palliative care specialist who was diagnosed with Alzheimer's disease, explained her decision to VSED:

> I choose to die by VSED because I want to avoid the long, relentless decline and the complete loss of self that is associated with the late stages of dementia… I don't want to be in twenty-four-hour care for years while I just am kept alive for the duration of time until I die and it is no longer a quality life. My choice is to give up a few good days to avoid bad years. To me, bad years means living in a facility, being cared for by others, no longer recognizing my family, losing my individual personality, and looking out at the world with a blank stare like the stare my mother gave me in her final days. This scenario is not the quality of life for me. Instead, it represents loss of dignity and loss of independence.[224]

An eighty-year-old physician with end-stage pancreatic cancer, Dr. Miller, explained it similarly: "I am extricating myself from a wretched end of life…"[225] Referring to his cancer, Dr. Miller, who had been a surgeon in his practice stated: "I will not allow it to make me suffer in these last few days…"[226] He further explained: "I've seen too many cases of patients with hopelessly fatal illnesses too often die with a tube down their windpipe in their last days…"[227]

Numerous studies of VSED patients and their caregivers show that the above statements are typical of those who choose VSED. Some express the desire to have "a

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[222] *See id.* at 74-76 (explaining impact of empathy on healthcare system).

[223] *See id.* (explaining benefits of empathetic providers). It is necessary for providers to display emotional empathy to effectively care for patients with different racial, ethnic, religious, and medical backgrounds. *Id.* at 75. Eliminating bias in healthcare impacts both patients and providers. *Id.* at 76. Patients who receive quality, empathetic medical treatment experience greater trust in the healthcare system and providers experience less professional burnout. *Id.* Additionally, when provider prioritizes the individuality of each patient, they are less likely to make medical mistakes and more likely to see an improvement in their reputation. *Id.* at 74-76.

[224] *See* END OF LIFE WASH., *Cindy's VSED Statement*, at 7:20 (YouTube, Aug. 16, 2022), https://www.youtube.com/watch?v=ed0ti0PUGSk (on file with the Suffolk University Journal of Health &and Biomedical Law) (showing patient decision to die by VSED).

[225] *See* CONCORD MEDIA, *Dying Wish*, at 0:25 (Vimeo, Jan. 3, 2017), at .48 https://vimeo.com/ondemand/dyingwishfilm (on file with the Suffolk University Journal of Health &and Biomedical Law) (highlighting another patient story).

[226] *Id.* at 1:06.

[227] *Id.* at 2:20.

sense of control over life and/or death."[228] Others speak of their wish to avoid pain. Some tell of their fear of being dependent.[229] Others tell of their comfort and acceptance of "having finished life."[230] Some express a preference for "VSED over MAID because VSED is a more gradual and natural death."[231] Many of the individuals with Alzheimer's or other dementia who chose VSED explained that they knew, from their professional or personal experience what living for years in the end stages of Alzheimer's were like, and they wanted no part of that.[232]

In short, whatever our views about VSED may be, as members of society it is our ethical duty to behave compassionately towards those who have debilitating diseases such as Alzheimer's and related dementia and choose VSED. To do this, we need to inform ourselves about the reality faced by these individuals and treat them with empathy. In short, we do well to follow the advice of Dr. Helen Riess and show "a tender response to another's suffering."[233]

VII. Conclusion

This Article has examined some of the ethical issues surrounding Voluntary Stopping Eating and Drinking (VSED) by those with Alzheimer's or related dementia. If offers three lessons.

The first is that our twenty-first century needs a health care system that is adequately trained in diagnosing and caring for those with dementia diseases. It is hard to imagine that Dr. X or the three hospices meant ill will or intended, by their conduct, to bring about suffering to a patient. Their unethical conduct, more likely, arose from a lack of training in dementia diseases, in end-of-life options such as VSED, and in their professional responsibilities. More education is needed for health care providers regarding these issues.

The second lesson is that most of us do a poor job of facing our mortality. Dying is part of life. Alzheimer's and other dementia diseases bring an especially heartbreaking death. This Article has argued that it is our ethical duty to face our

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[228] *See* Bolt, Pasman, & Onwuteaka-Philipsen, *supra* note **Error! Bookmark not defined.** (analyzing patient motives to die by VSED). Patients reported that they chose to die by VSED as a way of remaining in control. *Id.* at 536.

[229] Mensger et al., *supra* note 33 (providing patient experiences with VSED).

[230] Antonia Kao, *A Dementia Patient Chooses VSED*, End of Life Choices CAL. (June 16, 2024), https://endoflifechoicesca.org/a-dementia-patient-chooses-vsed/ [https://perma.cc/FY2F-HTXT]; *see also* Mensger et al., *supra* note 33, at 3 (providing patient experiences with VSED). Individuals who were with someone, either a patient or loved one, who died by VSED described it as "a beautiful and amazing experience and the dying process as calm, peaceful and not stressful for the patient." Mensger et al., *supra* note 33, at 3.

[231] *See* Bolt, Pasman, & Onwuteaka-Philipsen, *supra* note **Error! Bookmark not defined.**, at 536 (Patients expressed preference for VSED over PAD so they may have a gradual and more natural death. *Id.*; *see also* Mensger et al., *supra* note 33 (providing patient experiences with VSED). Individuals who were with someone, either a patient or loved one, who died by VSED described it as "a beautiful and amazing experience and the dying process as calm, peaceful and not stressful for the patient." Mensger et al., *supra* note 33, at 3.

[232] Antonia Kao, *A Dementia Patient Chooses VSED*, End of Life Choices CAL. (June 16, 2024), https://endoflifechoicesca.org/a-dementia-patient-chooses-vsed/ [https://perma.cc/FY2F-HTXT] (highlighting family experience with dementia); *Phyllis Shacter*, Compassion & Choices (June 2022), https://compassionandchoices.org/stories/phyllis-shacter/ [https://perma.cc/VU2F-ZG44] (explaining decision for VSED because mother had Alzheimer's); *see also* Mensger et al., *supra* note 33 (discussing positive experience with VSED). Studies show that individuals with personal or professional experience with VSED have a more positive view of the process. Mensger et al., *supra* note 33, at 4.

[233] *See* Riess, *supra* note 210, at 76.

mortality, inform ourselves about our diseases and options when we enter our last stage of life, thoughtfully consider what we want and don't want for the end of our life, and take agency over our choices.

The third lesson is to understand what VSED, an end-of-life option few know about, brings to those with Alzheimer's and related dementia. No one wants to die. But for some, living throughout the last stages of dementia is worse. For these individuals, VSED provides the one thing that is still in their control. VSED allows them to die with the dignity with which they had lived. This Article has argued that as members of society, it is our ethical duty, whatever our own views on end-of-life decisions, to inform ourselves about the reality facing those with dementia, and respond to them with empathy.