My Advance Directive for Dementia Care

April 20, 2022 by Anne Giles, MA, MS, LPC

I wish to inform my health care providers, loved ones, health care surrogate, and health care agent of my treatment instructions in the event I lack capacity to give instructions myself. I am fully competent at this time. I have a separate, general advance directive in place, as well as a Durable Do Not Resuscitate Order.

I am a person with capacity and have considered all the options that are available to me. I value life very much, but I believe that to continue living in certain circumstances is worse than death. Quality of life is more important to me than the number of days I have left to live.

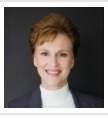
If I receive a diagnosis of a neurodegenerative disease causing symptoms termed "dementia," and/or I develop dementia, I consider this situation a terminal condition and a terminal illness with no known cure or effective treatment.

Under the conditions imposed upon me by dementia, including loss of my ability to understand my thoughts, selfhood and meaning, my inability to communicate comprehensively with loved ones or care givers, and my physical dependence on others for all aspects of bodily care, continuing life has no value to me.

This advance directive for dementia care should be applied when my dementia has progressed to the point at which, in the opinion of my health care agent,

1. *I do not recognize my family members, loved ones, and friends, and/or*
2. *I cannot remember their names, and/or*

Anne Giles



Anne Giles, M.A., M.S., L.P.C., is a counselor, speaker, and writer. She is the president and founder of Handshake Media, Incorporated. Read more…

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3. *I am not able to communicate well enough to make clear whether I recognize my friends and loved ones or remember them.*

Under these conditions, unable to connect meaningfully with others, I would wish to die peacefully and as quickly as legally possible. I do not wish to extend my life or prolong the dying process. I want to avoid a drawn-out, prolonged dying that would involve needless, protracted suffering for me and for those I love, tire care givers, and burden health care system resources.

Death with dignity

I request mercy.

If the Commonwealth of Virginia adopts a "Medical Aid in Dying" provision, in the case of dementia, I request that my attending health care provider prescribe a controlled substance that will end my life in a humane and dignified manner. I have informed my family of my decision and taken their opinions into consideration.

I understand the full import of this request, and I expect to die when I take the controlled substance to be prescribed. I make this request voluntarily and without reservation, and I accept full moral responsibility for my actions.

If Medical Aid in Dying is unavailable, I wish to be allowed to die by voluntary stopping of eating and drinking (VSED).

I intend that my health care agent alone be the one to determine whether I have reached the state to stop eating and drinking. I authorize my health care agent to take any legal action necessary to enforce my choice to die from voluntary stopping and eating (VSED).

If I begin to struggle to breathe at the end of life, develop dyspnea, am observed to develop "air hunger," and/or develop prolonged gasping respiration/agonal respiration, I consider this intractable suffering from a futile autoresuscitative mechanism and brainstem reflex. *In addition to* receiving analgesics and sedatives and being fully medicated for stress, distress, and pain, I request administration of a neuromuscular blocking agent.

Cessation of life-prolonging treatment

If I am unable to make informed decisions about my health, and I am unable to feed myself, I want all medications and treatments that might prolong my life to be withheld or, if already begun, to be withdrawn, including the provision of nutrition and hydration, whether provided artificially, medically, or by assisted oral feeding.

I wish to receive the best available palliative and hospice care and to refuse any medical treatment that would serve only to postpone my death, including, for example, vaccines, antibiotics, or other antimicrobial drugs, antiarrythmics,

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cardiopulmonary resuscitation, blood transfusions, or any artificial or mechanical means of life support.

Oral feeding

As a human adult, feeding myself is a vital human function and I am naturally able to feed myself. *If I am unable to feed myself or need assistance feeding myself*, my life has run its course. Being unable to eat and drink naturally occurs during the process of dying and I need to be allowed to die.

Although others may consider such measures personal care or comfort care, I consider oral feeding, spoon-feeding, and/or hand-feeding to be forms of medical treatment, medical procedures, and health care procedures and require the patient's consent.

I consider oral feeding and hydration unnatural, artificial feeding. Further, I consider oral feeding a violation of my bodily and existential integrity, privacy, and liberty.

Today, while I am competent, I withhold my consent to oral feeding and hydration. I specifically direct that oral feeding and hydration NOT be provided to me under the following circumstances.

If I am *unable to feed myself or need assistance*, and/or appear indifferent to being fed, do not willingly open my mouth, or expel, dribble out, or spit out foods or liquids, turn my head away when offered food or drink, hold food in my mouth or have the remains of food in my mouth after eating, and/or I cough, choke, gag, and/or aspirate food or liquid, I request I be allowed to die naturally by not eating or drinking. Specifically, *when I am unable to feed myself or when I need assistance feeding myself*, I wish to be allowed to die by voluntary stopping of eating and drinking (VSED).

No matter what my condition appears to be, I do not want to be encouraged, persuaded, cajoled, harassed, pushed, or forced to eat or drink. I do not want food or fluid to be held near my mouth to provoke me to open my mouth reflexively. *Even if I appear willing to accept food or fluid offered by assisted or hand-feeding, my instructions are that I do NOT want to be fed by hand even if I appear to cooperate in being fed by opening my mouth.*

I do not want the reflexive opening of my mouth to be interpreted as giving my consent to being fed or given drink, nor misinterpreted as a desire for food or drink. I request that spoons, other feeding implements, or cups not be touched to my lips or mouth. If I open my mouth, this is not a signal that I want food or drink. I consider this a sign of the "rooting reflex," or the "suck reflex," a primitive frontal release sign of the brain and nervous system that involves facial nerves. This reflex occurs automatically in infants and, in adults, is a sign of brain damage and neurological dysfunction.

If I hold food in my mouth or particles of food remain in my mouth, I consider this dysphagia, a common symptom of dementia and a sign of irreparable damage to the brain centers that control cranial nerves involved with swallowing. Food

Trauma

Uncategorized

remaining in my mouth is abnormal, uncomfortable, and puts me at risk of coughing, choking, and/or aspirating food particles and saliva into my lungs. Under these circumstances, I request no oral feeding.

I would like my lips and inner surfaces of my mouth and gums to be kept moistened to minimize discomfort. Moistening of my lips to keep them comfortable should not be considered a form of unrequested hydration.

Given that any other advance directive voluntarily signed while I am competent is honored after I lack capacity, even if I would die as a result, I request that my wishes regarding oral feeding be treated the same.

Alleviation of stress, distress, pain, anxiety, agitation, sleep disruption, and insomnia

I ask to receive good hygiene and other measures to assure comfort.

In a person with dementia, the configuration of destruction in the brain is unknowable. As the brain deteriorates, future configurations would also be unknowable. How these configurations would respond to medications is knowable only in the realm of possibility or probability, not certainty.

Regardless, I wish to receive *the highest doses possible of the most effective medications at maximum frequency for relief of* ***any*** *signs of stress, distress, pain, anxiety, agitation, sleep disruption, and/or insomnia.* Further, I want to receive medications in maximum dosages and with maximum frequency, including in excess of recommended dosages, to assure effective relief of emotional, mental, psychological, existential, and/or physical suffering ***even if this means I might sleep all the time, even though I might eat less or nothing, and even though such medications might shorten my life.***

Since dysphagia – difficulty swallowing – is a common symptom of dementia, I ask that this symptom be anticipated. I ask that medications be prescribed or compounded in liquid form as early as possible so I do not have to abruptly cease taking, or to taper from, helpful medications.

Since vital signs can remain stable during intense pain, vital signs are NOT an effective measure of pain in dementia patients. I ask that my pain, discomfort, and distress symptoms be monitored with pain and/or distress tools and scales developed by scientists for this purpose. As of this writing (2022), possibilities include the Abbey Pain Scale, PAINAD, and ePAT, although, as of 2014, no gold standard existed. I request that medications be increased or altered when I show pain or distress, even if I am already taking medications in high doses.

I ask that medication tolerance be monitored. For some medications used in palliative care, the brain and body adjust and the medications become ineffectual.

If and when my mental, emotional, existential, and/or physical distress becomes refractory, i.e. distress persists despite high-quality, aggressive palliative care, I request palliative sedation, the use of medications to induce decreased or absent

awareness in order to relieve intractable suffering at the end of life. I request palliative sedation even if I do not appear to be in physical pain. I consider palliative sedation to be distinct from assisted dying. Studies suggest that survival time is not significantly affected by palliative sedation.

I request that reassurance be given to my care givers that giving me medications, even in high doses, is giving me care. I do not fear addiction (continued use despite negative consequences), nor dependence (presence of symptoms when the medication is decreased or absent, tapered or withdrawn), nor palliative sedation.

I consider medications wondrous discoveries and inventions of science and wish to avail myself of the assistance of medications as fully as possible.

I understand that inaction and medications may cause constipation, a major consideration for those giving end-of-life care. I appreciate efforts to prevent what may be a painful or dangerous condition for me. Having done a cost-benefit analysis with rank ordering, I value the likelihood of medications providing relief from mental and physical suffering caused by dementia more highly than the possibility that medications may cause suffering through constipation or bowel damage. I ask that constipation or bowel damage not be a consideration when the dosage and frequency of pain and distress relief medications are decided.

Use of suppositories and/or insertion of a urinary catheter are disallowed medical procedures and require the direct consent of my health care agent.

Logistics

In the case of dementia, because my quality of life and my mental functioning will have declined significantly, with no hope of improvement, I wish to die as soon as possible.

I do not want others to substitute their choices for mine because they disagree with my decisions or because they think their choices are in my best interests. I do not want my intentions to be rejected because someone thinks that if I had more information when I signed this document, or if I had achieved certain spiritual or religious understandings, or if I had known certain medical facts that developed later, I would change my mind.

I want the instructions in this directive followed even if the person who has the right to make decisions for me and my caregivers judge, in their perception, that my quality of life is satisfactory and I appear to them to be comfortable. Their wishes may not supersede mine. I have given considerable thought to these decisions and want my wishes to be followed.

I insist that nothing I say or do be deemed a revocation of this advance directive unless I revoke it in writing at a time when I have the mental capacity to make and revoke an advance directive.

I ask that any health care institution providing treatment for me maintain all my advance directives in my chart and document prominently that these advance directives are in place, as required by national and state law.

I ask that my health care institution charge me and other funding sources fees high enough to pay my caregivers at the highest level of pay commensurate with their training and experience. Caregivers are using valuable, irreplaceable time in their own lives to help me with my life. I deeply value this. I ask that my health care institution pay for continuing education – including wages for the time it takes to complete the training – so my caregivers will know the latest science on caring for people in my condition.

I ask that the health care institution's management review these documents and determine if the health care institution has any policy against the enforcement of their terms. If so, I ask that I be transferred to an appropriate health care institution that does not have such a policy and will honor my wishes.

. . . . .

The primary source for this document is my first-hand experience with being unable to secure the honoring of the wishes of my father, Robert H. Giles, Jr.. He suffers from undiagnosed neurodegenerative brain diseases that cause the set of symptoms termed "dementia."

My sister and I are my father's designated health agents and I am his primary dementia care coordinator. My father has an advance medical directive and a supplemental document expressly stating his wishes in the case of dementia. Here are excerpts from that document, first signed in 1996: "If I get Alzheimer's disease or related diseases or disability, I need to die as soon as possible. I want this to occur. I want assistance in any and all ways possible that will not endanger family or friends or jeopardize them for court action…I'm writing what is my desire now since I believe that when I am in the last stages of illness I cannot decide anything. I need help in stopping my life when the appropriate time comes. Hard to know when such time has come, I believe it will be when any 3 people who know me think (expressed by their expert judgement) that I am operating mentally at less than 70% of my normal mental function."

The primary sources of contention – and why these portions are highlighted in my advance directive above – are:

1. Receiving effective medications, including anti-psychotics and opioids, early enough, and in sufficient doses, to ease mental and physical suffering including anguish-producing psychosis, hallucinations and delusions.
2. Definitions of "suffering."
3. Definitions of, and measurement of, "pain," including the documented inadequate management of pain in dementia patients, unknown pain caused by brain decay, and the unknown, possible alteration in pain perception caused by brain decay.
4. Archaic use of vital signs to measure pain. See, for example, Daoust et al., 2016 (!): "Health care professionals cannot use vital signs to estimate or substantiate self-reported pain intensity levels or changes over time."
5. Spoon-feeding.

My father trusted society to honor his clearly- and directly-stated wishes. He could not know that nearly thirty years later, in 2022, society would have become ascientific about medications and would prioritize prolonging life over relieving suffering.

My father asked me to share any parts of his story that might help others. I also wrote this:

- What I Wish I Had Been Told About Dementia

Update: My brave father died on May 5, 2022. Here is his obituary.

A selection of sources consulted follows. They are not in alphabetical order and not in accord with APA or other citation style guides. Some include excerpts.

"One option for ensuring that one does not live years in severe dementia is to use advance directives to withhold food and water by mouth. The driving element behind voluntary stopping of eating and drinking (VSED) is that forcing people to ingest food is as objectionable an intrusion on bodily integrity, privacy, and liberty as imposing unwanted medical treatment. Thus, if incompetent people do not lose their rights to refuse life-saving treatment, and if people when competent have just as strong a right to VSED as they do to refuse life-saving treatment, then people do not lose their right to VSED when incompetent either. They only have to exercise it by AD [advance directive]."
– Advance Directives, Dementia, and Withholding Food and Water by Mouth, Menzel et al., 2014

"Clinicians and health care societies have increasingly accepted voluntarily stopping eating and drinking (VSED) as an appropriate end-of-life exit option. If capacitated patients may hasten their deaths with VSED, then incapacitated patients should be able to exercise that same choice through an advance directive or health care agent."
Whether, When, and How to Honor Advance VSED Requests for End-Stage Dementia Patients, Pope, 2019

"Proponents view the practice [of VSED] as providing a humane exit option, particularly for dementia. Opponents see it as a denial of basic, morally obligatory care or as suicide. Still others focus on the clinical realities of institutional care and the practical difficulties involved in implementing 'Do-Not-Spoon-Feed' requests. Because VEN [Vermont Ethics Network] has started receiving inquiries about the practice, we discuss the issues it raises in greater detail below."
– Vermont Ethics Network, 2015

"Pain was the most common symptom (52%), followed by agitation (35%) and shortness of breath (35%). Pain and shortness of breath were mostly treated with opioids and agitation mainly with anxiolytics. At the day of death, 77% received opioids, with a median of 90 mg/24 hours (oral equivalents), and 21% received palliative sedation. Pain and agitation were associated with a lower QOL [quality of life]. Death from respiratory infection was associated with the largest symptom burden…Symptoms are common in dementia at the end of life, despite the large

majority of residents receiving opioids. Dosages may be suboptimal with regard to weighing of effects and side effects."
– Dying With Dementia: Symptoms, Treatment, and Quality of Life in the Last Week of Life, Hendricks et al., 2014

Causes and Signs of Untreated Pain in Dementia, Verywell Mind, 2021

On "a good death" and "dying well"

"Key to best practice end of life care are the actualization of human rights to dignity, autonomy, self-determination and respect for will and preferences, equitable access to quality health care that is needs-based, and respect for family and relationships…The human right to a good death and dying well is as important as the right to life. At stake at the end of life are human rights to dignity, autonomy, self-determination and respect for will and preferences, equitable access to quality health care that is needs-based, and respect for family and relationships. Older people with dementia, those with serious mental illness, and those with intellectual disability are vulnerable to 'bad deaths' due to violations of these rights."
– The Human Rights of Older People With Mental Health Conditions and Psychosocial Disability to a Good Death and Dying Well, Peisah et al., 2021

"Ten themes were identified, including pain-free status, peaceful/comfort, dignity, family presence, surrounded by familiar things and people, person-centered communication, spirituality, life completion, treatment preferences, and other."
Defining a good death for people with dementia: A scoping review, Takahashi et al., 2021

"Common themes [describing 'a good death' or 'dying well'] were dying at the preferred place, relief from pain and psychological distress, emotional support from loved ones, autonomous treatment decision making, avoidance of futile life-prolonging interventions and of being a burden to others, right to assisted suicide or euthanasia, effective communication with professionals, and performance of rituals."
– What would it take to die well? A systematic review of systematic reviews on the conditions for a good death, Zaman et al., 2021

"Participants perceived that there was ambiguity regarding a good death for PwD [patients with dementia] and emphasised the need for preparedness of those around PwD for a good death. Five categories represented preparedness: (a) reaffirming the original personality before dementia; (b) respecting that PwD change; (c) interpreting and fulfilling obscure desires, feelings, and sensations; (d) providing care consistent with an agreed-upon natural death process; and (e) maintaining relationships."
– Long-term care nurses' perceptions of a good death for people with dementia: A qualitative descriptive study, Nasu et al., 2021

"We identified 11 core themes of good death: preferences for a specific dying process, pain-free status, religiosity/spiritualty, emotional well-being, life completion, treatment preferences, dignity, family, quality of life, relationship with

HCP [health care providers], and other. The top three themes across all stakeholder groups were preferences for dying process (94% of reports), pain-free status (81%), and emotional well-being (64%)."
– Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue, Meier et al., 2016

"Core elements for a 'good death' included control of pain and symptoms, clear decision-making, feeling of closure, being seen and perceived as a person, preparation for death, and being still able to give something to others; whereas other factors such as culture, financial issues, religion, disease, age, and life circumstances were found to shape the concept across groups."
– Patient's Perspectives on the Notion of a Good Death: A Systematic Review of the Literature, Krikorian et al., 2020

"Class 1 results indicated health care providers' ability to control patients' pain to desired levels was most important (11.5%, 95% CI: 10.3%–12.6%), followed by clean, safe, and comfortable facilities (10.0%, 95% CI: 9.0%–11.0%); and kind and sympathetic health care providers (9.8%, 95% CI: 8.8%–10.9%)."
– What is a Good Death? A Choice Experiment on Care Indicators for Patients at End of Life, Sepulveda et al., 2022

When Her Husband Said He Wanted to Die, Amy Bloom Listened, New York Times, 2/27/22

VSEDs

- Final Exit Network
- New York
- Washington
- Oregon
- Discussion in Vermont

Virginia is considering a death with dignity law.

Here is the Code of Virginia Article 8. Health Care Decisions Act.

Here is the Virginia Advance Health Care Directives Registry.

Here is the National Institute of Health's guide to Legal and Financial Planning for People with Dementia.

Books

- Butler, Katy. *The Art of Dying Well: A Practical Guide to a Good End of Life*, 2019
- Gawande, Atul. *Being Mortal: Medicine and What Matters in the End*, 2014
- Yalom, Irvin. *Staring at the Sun: Overcoming the Terror of Death*, 2008
- Yalom, Irvin and Marilyn Yalom. *A Matter of Death and Life*, 2021

On this site, I have written posts about being a dementia caregiver.

Last updated 7/2/22

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A Research-Informed Protest Against Reliance Upon Vital Signs to Assess Pain in Dementia

Comments

Jeffrey D Martens says
April 20, 2022 at 10:42 AM
This is very important information for any family. My mother had severe dementia, was in hospice, stopped eating, and her hospice nurse had recently estimated that she had less than a week to live. I arrived at her memory care facility to find them trying to force her to eat. It was an ugly situation.

Anne Giles, MA, MS, LPC says
April 20, 2022 at 11:46 AM
Oh, Jeff, I'm so very sorry to hear this. Thank you for letting us know.

Jeffrey D Martens says
April 20, 2022 at 11:56 AM
Thing is, every family has end of life events to deal with. This was 5 years ago, but memories don't go away. You're being constructive: try to educate the people.

Anne Giles, MA, MS, LPC says
April 20, 2022 at 1:28 PM
You're helping. Thank you, Jeff.

Deborah Hamilton says
April 20, 2022 at 8:45 AM
Anne, Thank you so much for this post. It is the most informative, I have read.
DH

Anne Giles, MA, MS, LPC says
April 20, 2022 at 11:47 AM

Thank you, Deborah. My father's ardent wish that his story could be of help to others.

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