

INFORMATION for COMPLETING the attached Elective Advance Directive for Dementia

Introduction: If you live in the US and develop dementia, you have essentially four ways to deal with the condition: (1) live with the disease until you die, while receiving the best medical and palliative care available; (2) hasten your own death before the dementia renders you incapable of doing so; (3) refuse life sustaining medical care for any other medical conditions that you may have or that develop after dementia begins; (4) direct that you be allowed to voluntarily stop eating and drinking (VSED) after you have reached a certain point in the development of dementia; or some combination of these choices.

Background: The following Elective Advance Directive for Dementia is for use if you **do not want to live through the later stages of dementia**. The document is *intended for use as a supplement* to whatever advance health care directive you may have completed. These directives are sometimes called a living will, a Directive to Physicians, Advance Health Care Directive, or some similar name. This document can also be attached to your advance directive appointing someone to make health care decisions for you when you can no longer make them for yourself. For some people, the appointment of agent may be included in an advance health care directive. **When this dementia directive is attached to an existing health care directive or appointment of agent directive**, it should be referred to by name in that directive. If no space is provided in the directive for additional information, you can refer to this Elective Advance Directive for Dementia at the end of the directive, stating that it is a part of that directive for all intents and purposes.

State-formulated advance directives—which are only one way to make one's health care decisions known—were developed to (1) provide a standard form for use by that state's residents, and (2) provide clinicians protection from liability if the directives are followed. However, the constitutional right that we all have to make our views about health care known to clinicians can be exercised without the use of a form—by our own writing, orally (if competent), and/or by video. What is important is to **make your decisions known clearly**. In the words of an Idaho statute, “Any authentic expression of a person's wishes with respect to health care should be honored.” What a clinician should be guided by is understanding a person’s decisions, regardless of how they are expressed.

The failure of a clinician or health care facility to follow a clear directive may have to be addressed through an ethics committee or in a court of law. Both procedures may be time-consuming and expensive. When it comes to health care decision-

making, there are long-standing common law and constitutional principles of self-determination and liberty that should be followed by all clinicians and health care facilities. The courts should not require any particular form for conveying those decisions. The suggestions in these instructions and the supplemental directive are meant to provide the greatest chance of success in having your decisions followed. By statute or regulation, however, some jurisdictions may not permit using advance directives for VSED. Prof. Thaddeus Pope has explained that this is the situation in Wisconsin. See his discussion at *The American Journal of Bioethics*, 19(1): 90-97, 2019.

Prof. Pope suggests that one solution to the VSED dilemma in jurisdictions that may prohibit forgoing spoon feeding is to transfer the patient to a facility in a state or jurisdiction where it is not prohibited. However, **spoon feeding** against a person's clear directive and wishes is an **assault against the patient**, even in states and jurisdictions that mandate life-sustaining measures. This realization may cause some facilities to seek legal guidance in how to address this conflict between a patient's clearly stated directive and a statutory prohibition that may be legally or constitutionally questionable. It may be recognized, also, that an agent may not be agreeing with what is a clear and unambiguous prohibition by the patient against spoon feeding, but simply requesting that the patient's directive be followed. And a person's clearly-stated health care directive should be given priority over contrary public policy considerations.

Instructions: When completing the dementia supplement, be sure to (1) fill in all the blanks and (2) initial all **applicable** provisions in the list of symptoms and at the bottom of each page. The signing of this Elective Advance Directive Supplement for Dementia should be witnessed by two adults and/or acknowledged by a notary. It is probably best to complete the supplemental directive in the same way your state's advance health care directive or appointment of health care agent form is required to be completed; that is, use witnesses or a notary, or both, if your state requires or allows that. If witnesses are used, **most states have specific requirements about who cannot be a witness**. Generally, witnesses (1) may not be related to the person making the directive (the Maker), (2) be a beneficiary of the estate or life insurance of the Maker, or (3) be someone providing medical or caregiving services to the Maker. These requirements for witnesses are usually found in the instructions for the above-referenced directives of each state, and should be followed when signing this directive.

[This directive was developed for an adult education presentation on end-of-life choices involving dementia by Lamar W. Hankins, JD, with the gratefully received assistance of others – lamarhankins@mac.com]

Elective Advance Directive Supplement for Dementia
of _____
(name of maker)

This directive is a supplement to my health care advance directive and/or to my appointment of health care agent directive, whatever they may be called officially, executed in _____ (name of state) on _____, 20___. It explains the care and/or treatment that I want to receive if I have dementia. It represents the decisions I have made while mentally competent. If, in the future, I am no longer mentally competent, this supplemental directive may not be altered in any way and should be fully implemented by my caregivers, physicians, other medical personnel, and the health care agent I have previously named, as well as any subsequent health care agent named by me while legally competent or appointed by a legal authority. Health care agents are required to follow my wishes and directives, whether or not they agree with them. This is the duty they accept when they agree to serve as a health care agent.

It is my decision not to live through the later stages of dementia. In order to assure that this decision is honored, I direct the following:

1. Conditions for triggering this directive. Listed below are conditions that might develop as a result of dementia or during the time I have dementia. Beside each condition that I want to apply to me, I have placed my initials, indicating that it is a condition that should be used in triggering the effect of this directive. When, in the opinion of my medical agent and primary care or a treating physician, based upon clear and convincing evidence, I exhibit **all** of the conditions chosen, as indicated by my initials, I direct that this supplemental directive be followed:

- ___ loss of ability to read and understand a newspaper
- ___ loss of ability to make choices about food
- ___ loss of ability to recognize and identify the following family and friends:

- ___ loss of capacity to enter into contracts
- ___ loss of capacity to make medical decisions
- ___ loss of capacity to give consent to sexual activity with another
- ___ loss of ability to write with comprehension
- ___ disruptive behavior more than _____ times in a 24-hour period (for example, yelling, cursing, unprovoked anger, hitting, spitting, or other assaultive conduct)
- ___ confusion for at least _____ weeks about where I am or what day it is
- ___ inability to engage in conversations with comprehension

- _____ need for round-the-clock assistance with daily activities as a result of the loss of the ability to cook and prepare meals, to feed myself, to dress myself, to bathe myself, to toilet myself, to take medication
- _____ exhibiting increased risk of wandering and becoming lost
- _____ need for care in a nursing home or group facility for dementia patients
- _____ loss of the ability to walk
- _____ loss of the ability to sit
- _____ loss of the ability to swallow
- _____ other condition/behavior: _____

2. Directives following triggering

A. **When this directive has been triggered**, I direct that if I have other significant health problems (for example, diabetes, kidney failure, sepsis, other infections, a heart condition) for which I am being treated, and from which I will die without treatment, this treatment should be discontinued so that I may be allowed to die from that condition, provided that I am given comfort care until my death. If I have a **pacemaker**, without which I will die from heart failure, I direct that it be turned off and that I be provided palliative care. An exception to this provision is that if I take a **blood thinner to prevent stroke**, I want to continue that treatment to keep from becoming a stroke victim with dementia. Any other similar exceptions should be decided by my health care agent in accord with this directive.

B. When this directive has been triggered, I direct further that I not be treated for any new health problems that have the potential to end my life, such as, but not limited to, renal failure, pneumonia, heart failure, or infections. If my heart stops beating or I can't breathe on my own, do not shock my heart to restart it or attempt any other resuscitation, and do not place me on a breathing machine. Instead, if either of these happens, allow me to die peacefully. I should not be taken to an emergency room or a hospital except to receive comfort care.

C. When this directive has been triggered, **I do not want to receive food or liquids by mouth through self-feeding, hand-feeding by another, or by other medical means**. This is usually termed *Voluntarily Stopping Eating and Drinking (VSED)*. I consider nutrition and hydration, whether natural or artificial, and by whatever method it can be provided, to be medical treatment or therapy under the circumstances described in this directive, and I have determined that they are not acceptable medical treatments or therapy for me under the circumstances described

above. To feed me by hand will be an assault on my body and prohibited under tort and criminal law.

D. To carry out my decision for VSED effectively, **I direct that no one be permitted to offer me food, liquids, or artificial nutrition or hydration by medical means**; nor may anyone bring food into my presence or within range of my ability to smell it or see it. Bringing food into my sensory range could result in involuntary or agitated reactions which could lead to additional suffering, or be misinterpreted by observers as a desire for such nutrition or hydration.

E. Once this supplemental directive is triggered, as described above, **no comments made by me, utterance, gesture, or action should be interpreted to mean that I am over-riding this supplemental directive because I will, at that point, be mentally incompetent** and legally incapable of forming a rational understanding of what is happening to me or be able to appreciate the consequences of changing the terms of this supplemental directive.

3. Palliative (comfort care) directives

A. I want at all times to receive **palliative, comfort-oriented care**; that is, care focused on relieving my suffering from pain, anxiety, breathing difficulty, or other adverse medical or health conditions. Such palliative care should be part of all medical treatment and care I receive, regardless of any other decision made in my advance directive and this supplement.

B. **Oral care:** The use of cracked ice by mouth to relieve any dryness around my lips and mouth is acceptable and necessary care, as are other treatments for such dryness in order to keep me comfortable. If I am able to swallow, and taking medication by mouth is appropriate under this supplemental directive, I may take fluids only as are necessary for the administration of the medication.

C. **Sedation.** If VSED, medical or health conditions, or circumstances other than dementia begin to create physical pain or unnecessary suffering, palliative care may necessitate sufficient sedation to make me semi-conscious or unconscious. I approve such sedation, fully realizing that it may result in a hastened death, though that will not be its purpose.

Summary, signature, and notary acknowledgement

I understand what this document means and all of its implications. I make this document of my free will, and I have the mental and emotional capacity to do so.

By signing below, I indicate that I understand the purpose and effect of this document, and that I am giving my informed consent to only the treatments and care that I have directed.

Signature of maker: _____ Date: _____

WITNESS ACKNOWLEDGEMENTS

I declare that I personally witnessed the signing of this Elective Advance Directive Supplement for Dementia by the Maker, who is known to me and who appeared to be of sound mind at the time of signing:

Name of first witness: _____

Signature: _____ Date: _____

Name of second witness: _____

Signature: _____ Date: _____

NOTARY ACKNOWLEDGEMENT

STATE OF _____

COUNTY OF _____

I, the notary public named below, certify that I know or have satisfactory evidence that _____, on the _____ day of _____, 20____, signed this document in my presence and acknowledged it to be his/her free and voluntary act for the uses and purposes set forth in this document.

NOTARY PUBLIC in and for the State of _____
My commission expires:
