INSTRUCTIONS

EARLY DEMENTIA DIRECTIVE

FOR THOSE WHO KNOW OR STRONGLY BELIEVE THEY HAVE EARLY DEMENTIA
INCLUDES **S**TOPPING **E**ATING AND **D**RINKING (SED) AS A CHOICE

***Basic Choices**:* This directive is for people with early dementia who want to be proactive dealing with their progressive disease. If your wish is to let nature take its course and do nothing, this form is not for you. If you want to prevent living to end-stage dementia, this form discusses three basic choices:

1) Before Decisional incapacity sets in, undertake **V**oluntary **S**topping **E**ating and **D**rinking (VSED) to end your life. Of course no advance directive is necessary for VSED, but having one is advisable.

Use this form to:

2) Direct that steps be taken to prevent any treatment that might extend your life. If another disease might end your life before dementia does, so be it.

3) Direct that your agent prevent you from eating and drinking, thus causing you to die by dehydration. This is called **S**topping **E**ating and **D**rinking by **A**dvance **D**irective (SED by AD). (This form is that directive.)

***No Diagnosis**:* This form may also be used by people who don't have a medical diagnosis but believe strongly that they have dementia because their memory has been gradually failing – more so than from normal aging.

***Time to Complete**:* Don't rush to complete the form. Give its choices a lot of thought.

***Do research**:* Discuss the form and its choices with your family, your doctor, you agents, and others whose opinion you respect. Good information on VSED can be found at Compassion and Choices, https://compassionandchoices.org/?s=stopping+eating+and+drinking; for scholarly but easily readable discussions of both VSED and SED by AD, go to *Voluntarily Stopping Eating and Drinking, a Compassionate, Widely Available Option for Hastening Death* (Oxford University Press, 2021).

***Letter to your Agents**:* You are urged to write a separate letter to your agents. It need not be notarized or witnessed. Such a letter gives you an opportunity to state in your own language your thinking, your wishes and your attitude toward death and your disease. It will help your agents carry out your wishes when a specific situation is not covered by this form. The letter can be changed later so long as it is consistent with this directive.

Get an Advocate*:* Your agents must be strong advocates for your choices, even if they don't agree with them. Discuss this with them. Your best agents may not be members of your family.

Medical care**:** Medical care is not necessary but is advisable. In the beginning, given no other disease, the minimum care needed can be provided by the family. But near the end of the process, and even before, it is advisable to have available someone experienced with the care needed. Besides a doctor, such care can be provided by nurses and nurse practitioners, physician assistants, and even death doulas. The best provider may be a hospice. But whoever it is, it is critical that they have experience with people dying from SED.

BE AWARE: In some states SED by AD (after capacity is lost) is likely unlawful; the agent and others involved in the death are at criminal risk. Wisconsin appears to be such a state. In others, such as Nevada, Vermont and Arizona, SED by AD seems to be legal based on statutory language. In the remaining 46 states the law is not clear. Because no court decisions have been found on this issue in any state, this could be said of all of them. The issue is, are food and fluids medical treatments that the agent has authority to withhold? Some doctors have argued that they are not. Law professor Thaddeus Pope has argued that they are. So carrying out SED by AD has risk, but far less in Nevada, Vermont and Arizona.

Where you Live*:* Your decision to undertake VSED or to instruct your agent to undertake SED by AD may be tempered by where you live. There is more concern by the authorities for hastened deaths in conservative jurisdictions than in moderate or liberal ones.

Why All Users Should Complete Sections TWO and THREE*:* If you are planning VSED so don't need an early dementia directive, and you are following the advice to execute this directive nonetheless, you might later change your mind about doing VSED, so complete all sections. If you do not want SED by ED, cross through SECTION THREE and initial and date it.

Capacity**:** This form must be completed while you still have decisional capacity.

USE in STATES OTHER THAN CALIFORNIA: Attestation requirements for executing advance directives vary from state to state. This form meets California's requirements. If you are in another state, check their requirements. Often using a notary rather than witnesses is sufficient.

Print your name here: _____

Please read the instructions before filling out this form.

ADVANCE DIRECTIVE FORM FOR PERSONS WITH EARLY DEMENTIA

My Name is: _____ _____

Full Name Preferred First Name

My Agent (Surrogate or Proxy) is: _____

Agent's Phone Numbers: _____

Cell Home Work

Address: _____

My Alternate Agents are: (If the designated agent is unwilling or unable to serve) (Optional)

1st Alternate: Name: _____

Phone Numbers: _____

Address: _____

2nd Alternate: Name: _____

Phone Numbers: _____

Address: _____

My Primary Physician is:

Dr. _____

Phone: _____

Address: _____

AUTHORITY OF MY AGENTS: When I am unable to make my own decisions, my Agents have authority to make all medical decisions for me. This means to consent, refuse, or withdraw any medical care, such as surgery, medications, or procedures, even if deciding to stop or withhold treatment might hasten my death.

INSTRUCTIONS TO MY AGENTS: I have discussed my philosophy, goals and wishes with you, and may have put them in a letter to you. If the choice I would make in any given circumstance is unclear, you are instructed to decide based on what you believe to be in my best interest, given my philosophy, goals and wishes known to you.

INSTRUCTIONS TO MY PERSONAL AND ATTENDING PHYSICIANS: The quality of my life is more important to me than living as long as possible. I understand that doctors, nurses and others have a professional obligation to keep me alive. It is my directive that such obligation

Print your name here: _____

is (1) less important than my autonomy as expressed by my choices herein, and (2) less important than my desire to not prolong my life with dementia.

SECTION ONE

MY STATEMENTS

1. I have been diagnosed with early-stage dementia (_____). [name the specific disease.] OR if checked or Xed here _____I strongly believe that my memory is gradually failing, more so than if caused by normal aging. I am choosing this form because I believe I have early dementia.
2. I still have decision-making capacity. I know that I am making decisions that are intentionally designed to shorten my life. I have discussed my decisions in this directive with my agents, and with others, namely_____ My agents understand that, if so indicated in this directive, they are to end my life by withholding medical treatment and even by withholding food and fluid from me.
3. I have ___ [or have not ____] written a letter to my agents.
4. POLST**.** I have ___[or _____ I do not have] a doctor's POLST order, or similar doctor's order (many states have a different name for a POLST-type order).
5. I believe that food and fluids are medical treatments.
6. VSED. I may ____ [or I do not plan to _____] end my life via VSED before permanently losing decisional capacity caused by my dementia.

SECTION TWO

MY DIRECTIVES OTHER THAN SED

(Check or X all that apply)

Complete this SECTION TWO and SECTION THREE regardless of how you answered #6):

_____ **Palliative Care.** Always provide palliative care to keep me comfortable.

_____ **Pain.** If I have pain, treat it, even if the treatment will shorten my life.

_____ **DNR/DNI** If I suffer a heart attack or stroke, do not attempt resuscitation or intubation (forced breathing).

_____ **Treatments.** Don't give me any treatment that may prolong my life.

_____ **Diseases.** If I am diagnosed with some disease that may shorten my life, don't treat it.

_____ **Infections.** If an infection might be serious enough to shorten my life, don't treat it.

_____ **Comfort Feeding Only**. If I don't desire to eat or drink, don't force me to. Do not feed me intravenously or otherwise.

_____ **Persuasion.** Don't entice me in any way to eat or drink.

_____ **Odors.** Keep food and food odors out of my room.

_____ **Palliative Sedation.** Provide palliative sedation if needed, even if it shortens my life.

Print your name here: _____

SECTION THREE

MY DIRECTIVES RELATING TO SED

If my incapacity is due to some cause other than my dementia, then **this** SECTION **still** applies.
(Check or X all that apply)

SED by AD (**S**topping **E**ating and **D**rinking pursuant to this **A**dvance **D**irective, after my incapacity):

_____ I direct my agents (and as necessary my family and my care givers) to cease feeding me and giving me liquids, when any one ___, or any two ___, or any three ___ of the following occur:

_____ I am in a vegetative or near vegetative state.
_____ I am a financial strain on my family.
_____ I say that I don't want to live any longer.
_____ I don't recognize my family.
_____ My personality changes so much that I am angry or lash out at people.
_____ I have hallucinations, such as fearing people or things that don't exist.
_____ I can't get out of bed on my own.
_____ I can't control my body wastes.
_____ I require constant assistance.

Other:_____
_____

This SED by AD advance directive applies even if I ask to be fed or ask for liquids -- my demented wishes and utterances must be ignored.

Exception to SED by AD. If my agent, family or caregivers are at criminal risk for following this directive, and they don't wish to assume the risk (and I don't expect them too), then this SED by AD directive is to be ignored.

_____

Possible way around the risk problem: my agent and my family have my permission to move me to a state where there is no significant legal risk. At the time of writing this form, the states of Nevada, Vermont and Arizona have statutes that permit SED by AD. My estate is to pay the cost of moving me and my lodging.

SPACE FOR YOUR ADDITIONAL TERMS (or attach a page):

_____
_____

Print your name here: _____

SECTION FOUR

MISCELLANEOUS PROVISIONS

AGENTS: My use of the term "my agents" in this directive does not mean that I have more than one agent at a time.

LIVING ARRANGEMENTS: If I am in an institution or any facility that refuses to carry out my directives, then move me home or to a facility that will.

CONSERVATORSHIP/GUARDIANSHIP: If a conservatorship/guardianship of my person needs to be appointed for me by a court, I nominate the agent designated in this form.

AFTER-DEATH WISHES (Initial those that apply):

Organ and tissue donation:

_____I wish to donate any and all of my organs and tissues.

_____I wish to donate only the organs or tissues listed here:

_____

Autopsy:

_____ My Agent is authorized to allow or request an autopsy.

Disposition of Remains:

_____ My Agent is authorized to direct the disposition of my remains.

_____ I have left specific after-death instructions which may be found at or in:

_____

SIGNATURE

Sign here:_____Date: _____ 20____

(In order for this form to be complete and effective, your signature must be notarized or witnessed (usually by two persons), as required by the laws of the state in which you reside).

Print your name here: _____

WITNESSES for CALIFORNIA ADVANCE DIRECTIVE

Or sign in front of a Notary

STATEMENT OF WITNESSES:

I declare under penalty of perjury under the laws of California:

(1) that the individual who signed or acknowledged this advance health care directive is personally known to me, or that the individual's identity was proven to me by convincing evidence,

(2) that the individual signed or acknowledged this advance directive in my presence,

(3) that the individual appears to be of sound mind and under no duress, fraud, or undue influence,

(4) that I am not a person appointed as agent by this advance directive, and

(5) that I am not the individual's health care provider, an employee of the individual's health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.

WITNESS 1 Date: _____ WITNESS 2 Date: _____

_____ _____

Signature Signature

_____ _____

Print Name Print Name

PRINT ADDRESSES:

_____ _____

_____ _____

ADDITIONAL STATEMENT OF WITNESSES: At least one of the above witnesses must also sign the following declaration: I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance health care directive by blood, marriage, or adoption, and to the best of my knowledge, I am not entitled to any part of the individual's estate upon his or her death under a will now existing or by operation of law.

Signature: _____