STRATEGIC ADVANCE CARE PLANNING: An OVERVIEW

—To maximize success by minimizing how long and how much you may have to endure end-of- life suffering if you reach advanced dementia or similar terminal illness

Challenges

Imagine losing your ability to recognize loved ones, communicate your wishes, or recall what gives your life meaning. For over two million Americans living with advanced dementia—a number projected to double by 2050—this is reality. Terminal illnesses can rob you of decision-making capacity and prevent your refusing treatment that will only prolong your suffering.

Advanced dementia can create profound personal suffering through:

- Undetected and therefore untreated physical and emotional pain, which we call **Non-Observable Suffering** or **N-O-S**
- Progressive loss of personal identity until you hardly resemble the person you were
- Inability to recognize loved ones or communicate coherently
- Loss of memory to recall and share treasured events of your past; that is, your life
- Total dependence on others for basic needs, including eating and toileting
- Burden your family emotionally and financially (exceeding $125,000 annually)
- Years of unrelenting progressive deterioration with little ability to enjoy living
- Living in an extremely vulnerable state that some observers glibly dismiss by stating, "S/he's not suffering. S/he's just sitting there." This non-sequitur logical fallacy *assumes* you have inner peace by observing your outer withdrawal; then it makes an incorrect inference. It dangerously overlooks difficult-to-detect and inherently non-observable or non-current suffering. Two examples that current patient examination systematically miss in other living wills are: (A) Your illness imposes huge burdens on your loved ones; and (B) You will be leaving your survivors tarnished future memories of yourself that will be worse as your state of indignity continues to worsen.

Facts: According to Silveira and others, 43% of adults over 60 (for all diagnoses) rely on others to make end-of-life treatment decisions on their behalf since 70% lacking decision-making capacity.[1] For patients living with advanced dementia (**PLADs**), both figures approach 100%.

Problems with Conventional and "Dementia-Specific" Living Wills

Living wills may not be effective in granting you power to control *how* and *when* you die:

- Vague implementation criteria or conflict around "the answer to the 'When' question"
- Lack of evidence regarding whether you possessed decision-making capacity
- No strategies to overcome resistance from physicians, providers, or institutions
- Absence of legally binding relevant physician orders, such as a **POLST** (see below)
- No strategies against sabotaging your plan by others, like your "future demented self"

Dr. Terman's 2022 critical review identified two dozen flaws in existing dementia-specific directives that can lead to premature or prolonged dying.[2] Furthermore, no living will—until now—offers an effective strategy for incapacitated patients who can still eat and drink without assistance (independently). Dr. Terman characterizes these vulnerable people as living in the "Dementia Gap."[3]

The Solution: Strategic Advance Care Planning That Includes Two Treatments of Last Resort

Caring Advocates offers a comprehensive protocol to ensure your treatment preferences are not only clearly stated (which is where most living wills stop) but actually implemented in the future. Our evidence-informed, legal, ethical, and moral approach includes two treatments of last resort:

Natural Dying (ND) withdraws others' assistance with oral feeding and hydrating if you reach a condition that you previously judged (during ACP) would cause irreversible, **severe suffering**—if you are then dependent on assisted feeding to survive. If your reason to refuse food and fluid is because continuing will only prolong your dying and suffering, then your agent can argue that feeding you is u**nwanted, forced, and unnatural**. The protocol requires food and fluid to always be placed within your reach—to uphold the highest legal, ethical, and moral standards.[4]

Moderate Anesthesia (MA) provides you sedation to unconsciousness if (A) you are living in the "Dementia Gap" and (B) non-sedating treatments failed to relieve your **intolerable suffering**. The protocol includes stopping sedating medications after about four days so your physician can ask, "Has your rest restored your strength enough for you to now want to resume conscious living?" This "Respite Sedation" addition to the protocol helps you prove that your and your physician's intent was to relieve suffering—not to hasten your dying—so it was moral. And evidence that allows **MA** to be viewed as moral is critically required for it to be acceptable to authorities who have the power to say "No."

The Seven Steps to Strategic Advance Care Planning [5]

1. Complete Your Natural Dying Living Will

Using illustrated My Way Cards,[6,7] you'll make decisions about 50 specific clinical conditions. Unlike traditional directives, this patient decision aid:

- Features emotion-revealing illustrations and third-grade reading level text: High resolution color images display facial expressions that reveal your inner emotional state, word bubbles that help to clearly indicate the challenges faced, and thinking bubbles that detail how patients in this condition are affected by each condition
- Focuses on observable behaviors—not on debatable medical diagnoses (very little jargon)
- Addresses 40 conditions; other directives omit many and are not comprehensive
- In sum: the Natural Dying Living Will considers as high priorities, all sources ~~o~~f your physical, emotional, existential and financial suffering that affects you and your family.[7]

2. Consult With Your ACP Counselor

Through collaborative discussions, you'll ensure your advance treatment decisions:

- Maintain internal consistency among your treatment decisions
- Reflect your lifelong values and current treatment preferences
- Demonstrate deliberative, diligent decision-making
- Express specific clinical criteria to implement that future physicians/providers can accept
- Facilitate peace of mind now by professional collaboration: your Diligent Capstone Review

3. Form Your Patient Decision Committee (PDC)

Designate your healthcare agent, alternates, and trusted advocates who will:

- Act as steadfast advocates to take action so you attain end-of-life goal-concordant care
- Invoke specific relevant strategies as needed, to overcome many kinds of resistance
- Discuss and vote with other (PDC) members on the timing to implement specific treatments of last resort
- Provide mutual emotional support as agents make heart-wrenching existential decisions

4. Record Your Video Testimony

Create powerful video-memorialized evidence that:

- Demonstrates decision-making capacity and voluntariness without undue influence
- Presents your persuasive voice and face to convince your future physicians/providers
- Allows you to clearly, specifically, and credibly explain your underlying reasons
- Makes it nearly impossible for others to claim you did not understand your choices

5. Add Legally Supported Strategies

Our unique documents provide multiple layers of strategies to overcome common challenges:

- The Bilateral Durable Power of Attorney and the Natural Dying Agreement anticipate common potential conflicts based on two decades of clinical experience
- Strategic arguments cite statutes and case law to maximize potential success
- Prevent or quickly resolve emerging conflicts and sabotage. Example: your "future demented self" grunts and points to food and then to their mouth to indicate their current desire for assisted feeding to resume. Most laws require providing patients requested life-sustaining treatment—unless there is a clear and convincing counterorder. Also, you can make certain choices irrevocable, so the instructions in your past living will prevail

6. Include Specific "Future POLSTs"

Medical and legal characteristics contribute to POLSTs' effectiveness:

- Orders must be implemented immediately, which gives little time for conflicts to emerge
- Orders that do not conflict with the physician's moral conscience or general medical practice **must** be honored in **all** treatment settings (Conscience objection is rare.)
- Orders must be consistent with living will instructions (a strategic, added order)
- Emergency Medical Technicians and other 911 first responders' training includes the legal requirement to comply with POLSTs (or seek guidance from the base station MD)

Examples of specific POLST orders:

- Do everything, including CPR (cardiopulmonary resuscitation)
- DNR plus refusal of invasive/burdensome treatments, such as tube feeding, machine breathing, and other types of ICU interventions
- Comfort-focused treatments with Comfort Feeding Only (if eating is still pleasurable)
- Natural Dying for severe suffering
- Moderate Anesthesia for intolerable suffering, and sometimes for severe suffering if you can still eat and drink independently which makes Natural Dying (VSED) unable to work
- Voluntarily Stopping Eating and Drinking—if you still have decision-making capacity—a medical/legal insurance strategy so others cannot sabotage your end-of-life wishes
- Withholding Food and Fluid—if physician judges you at risk for aspiration pneumonia

7. Establish Secure Storage and Quick Access

Ensure your documents and videos are available when needed through:

- Secure digital storage in national registries
- Multiple copies so each designated agent has a set
- Patients can keep laminated contact cards with basic information in their wallet
- Patients can wear POLST badges with scannable barcodes to access documents & videos

Benefits of Strategic Advance Care Planning

Completing Strategic Advance Care Planning will likely afford you a significant **reduction** of:

- Your fear of getting "stuck" with prolonged suffering in an advanced stage of dementia
- Your loved ones' or decision-makers' burdens including existential angst
- Your grief that can be complicated by understanding and addressing "ambiguous loss"
- Your healthcare providers' moral toll
- Your receiving unwanted, burdensome, futile, non-beneficial treatment
- Your need to seriously consider prematurely orchestrating an end-of-life-end option that would have needlessly sacrificed months to years of challenging but still satisfying living

The goal of Strategic Advance Care Planning is to make it possible for you to live as long as you can enjoy living without severe suffering. Our slogan summarizes this achievable goal:

Plan Now to Die Later™—to Live Longer

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NOW Care Planning

For incapacitated patients who face a terminal illness with severe suffering (estimated at over 1.5 million people), but now lack an effective living will, we offer NOW Care Planning—an alternate protocol that can address their urgent needs.[8] To learn more, (A) Read the description on the website; (B) Experience the Demo using the link above, so you understand how the patient decision aid works; and (C) Contact Caring Advocates about your relative.

About Caring Advocates

Founded in 2000 by bioethicist/psychiatrist Stanley A. Terman, (AB, Brown) PhD (MIT), MD (University of Iowa), Caring Advocates develops protocols whose goal is to reduce end-of-life suffering based on our extensive clinical experience and peer-reviewed research. (Dr. Terman's full CV is at www.CaringAdvocates.org.)

Take the Next Step—How to CONTACT Caring Advocates

Email DrTerman@CaringAdvocates.org or 800-64-PEACE (647-3223) to begin Strategic Advance Care Planning. Learn more about NOW Care Planning at www.caringadvocates.org. Experience a demonstration version of My Way Cards at tinyurl.com/MyWayCardsDEMO. For a prompt response, text 760-704-7524.

Other Relevant Citations

(Note: Copy and paste the underlined URL beginning with "10" to view/download articles.)

Volicer L, Pope TM, Steinberg KE, Terman SA. Response to Resolution A19 Regarding "Stopping Eating and Drinking by Advance Directives". J Am Med Dir Assoc 2023;24(6). DOI: 10.1016/j.jamda.2019.04.010

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1 Silveira MJ, Kim SY, Langa KM. N Engl J Med. 2010;362:1211-8. DOI: 10.1056/NEJMsa0907901

[2] Terman SA, Steinberg KE, Hinerman N. Flaws in advance directives that request withdrawing assisted feeding in late-stage dementia may cause premature or prolonged dying. BMC Med Ethics 2022;23(1):100. DOI: 10.1186/s12910-022-00831-7

[3] Terman SA. Timely dying for patients living in the "Dementia Gap": If their suffering becomes exceedingly severe, is it moral to sedate them to unconsciousness? (work-in-progress; available upon request)

[4] Terman SA. Can an effective end-of-life intervention for advanced dementia be viewed as moral? Alzheimers Dement (Amst) 2024;16(1). DOI: 10.1002/dad2.12528

[5] Terman SA. Seven Steps to Strategic Advance Care Planning (25 pages) available at https://caringadvocates.org/Seven-Steps-to-Strategic-Advance-Care-Planning-Caring-Advocates.pdf

[6] Terman SA. Relieving Refractory Suffering in Advanced Dementia with an Advance Care Planning Protocol, or a Protocol for Late-Stage Patients who Lack Directives, can be Effective, Legal, and Moral (work-in-progress; available upon request)

[7] Terman SA, Steinberg KE, Hinerman N. Timely dying in dementia: Use patients' judgments and broaden the concept of suffering. Alzheimers Dement (Amst) 2024;16(1). DOI: 10.1002/dad2.12527 (See also: www.CaringAdvocates.org)

[8] Terman, SA. https://caringadvocates.org/newstuff/SIX-STEPS-to-NOW-Care-Planning.pdf

1