STRATEGIC ADVANCE CARE PLANNING: An OVERVIEW

—If you want to minimize how long and how much you may endure end-of-life suffering, especially if you reach advanced dementia or a 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
- Progressive loss of personal identity until you hardly resemble your previous self
- Inability to recognize loved ones or communicate coherently
- Loss of memory to recall and share the most treasured events of your past
- 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. Examples: Your illness imposes huge burdens on your loved ones. Leaving your survivors tarnished future memories of yourself in a state of indignity.

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 unwanted, 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 exceedingly severe suffering. The protocol includes stopping sedating medications after a four-day rest so your physician can ask you, "Has your rest restored your strength enough for you to now want to resume conscious living?" This "Respite Sedation" addition to the protocol helps that prove you and you physician's intent was to relieve suffering—not to hasten your death—so it was moral.

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
- Focuses on observable behaviors rather than on debatable diagnoses
- Addresses many conditions other directives omit, in striving to be comprehensive
- Considers your emotional and existential suffering, and your family's suffering[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
- Meet with other (PDC) members to vote if it is time to implement specific treatments
- 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, clearly, and credibly explain the reasons underlying your decisions
- 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 must generally be honored in all treatment settings
- Orders must be consistent with living will instructions (an added order)
- Emergency Medical Technicians and other 911 first responders training includes the law requires them to comply or to seek guidance from the medical officer at their base station

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 exceedingly severe suffering
- Voluntarily Stopping Eating and Drinking—if you still have decision-making capacity
- 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 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 complicated grief, through understanding and addressing "ambiguous loss"
- Your healthcare providers' moral toll
- Your receiving unwanted, 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

What Strategic Advance Care Planning does **not** reduce but promotes:

- Your ability to live as long as you want if you're not suffering and capable of enjoyment

Our slogan summarizes this achievable goal:

Plan Now to Die Later™—to Live Longer

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A no-obligation opportunity to experience using this patient decision aid:
Use this link for a Demonstration that includes 12 (of 50) Conditions/My Way Cards:
tinyurl.com/MyWayCardsDEMO

(*You can skip the redundant "Introduction" written for patients with low literacy or reading comprehension.*)

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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—a companion 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 to reduce end-of-life suffering based on our clinical experience and peer-reviewed research. (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] https://caringadvocates.org/downloads/SIX-STEPS-to-NOW-Care-Planning_2019-07-22.pdf (Currently being revised)

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[1]

Effective Advance Care Planning for Late-Stage (Advanced) Dementia:

Can it Reduce How Long and How Much Patients Suffer—and Still be Moral?

Stanley A. Terman, PhD, MD; Caring Advocates
Bioethicist, Board Certified in Psychiatry
San Francisco End of Life. May 7, 2025

Beyond Suffering in Silence: The Agony of Non-Observable Suffering in Advanced Dementia

Imagine visiting Sarah, now in her eighth year of progressive dementia. Day after day, year after year, she sits confined to the hallway of a stark healthcare facility. Slumped over in a wheelchair with restraints, she exists in a chemically sedated state rather than receiving social stimulation. Staff largely ignore her unless her occasional difficult behaviors demand attention—episodes that ironically trigger increases in her monthly care fees. The escalating expenses for her continued care are rapidly draining her family's finances, threatening not only their educational and business opportunities but potentially forcing them toward the devastating prospect of medical bankruptcy.

Most observers see Sarah sitting quietly, appearing peaceful or asleep. Yet beneath this facade of serenity lies profound, largely invisible suffering. Dementia has severed all her meaningful connections by destroying her ability to recognize loved ones, communicate coherently, or recall memories of shared peak life experiences. She now endures unobservable loneliness and profound loss of identity since she is deprived of personality-defining interactions that relationships had always provided.

Dementia has disrupted Sarah's life narrative, so she no longer can function as a family member, colleague, and recreational partner. This erosion has stripped away her fundamental sense of purpose and meaning.

Sarah also suffers from being unable to protect her loved ones from their own emotional trauma. They endure multiple forms of distress: the “slow goodbye,” as dementia gradually erases the person they once knew; the helpless anguish of witnessing relentless decline; and the disorienting “ambiguous loss” where the physical Sarah continues to exist while the mental Sarah has almost completely disappeared.

Her suffering often becomes chronic because casual observers—including many professionals—dismiss it with this or a similar superficial judgment: “She’s not suffering. She’s just sitting there.” This dangerous non-sequitur fallacy equates outward calm—which is actually pathological withdrawal—with inner peace, since Sarah may actually be experiencing profound depression as a result of her existential isolation.

Also heartbreaking is Sarah’s haunting dread that her family will primarily remember these undignified final years—a time when she required complete assistance for basic needs, including having caregivers change her diapers due to chronic fecal incontinence—rather than the vibrant who made many contributions to society: the person she once was.

This composite patient story illustrates why we must ardently intensify our approach to the care, dignity, and decision-making of incapacitated patients, such as those living with advanced dementia. It compels us to honor patients’ authentic wishes expressed before loss of capacity. It motivates to investigate sources of suffering more vigorously. Finally, after suffering has become irreversibly severe, to provide goal-concordant end-of-life care. If consistent with their expressed values, to implement treatments of last resort to relieve their suffering and allow them to die naturally from their underlying disease.

—An excerpt from an article that Dr. Terman will soon submit for publication.

Still be Moral, Why it Matters:

Treatments of last resort are controversial. If life ends, it’s irreversible. Everyone wants to be sure it’s the right act at the right time.

Advance care planning (**ACP**) cannot be successful unless a physician/provider agrees to implement the orders patients need.

Physicians, other providers and their health care institutions may refuse to honor patients’ wishes if they lack confidence that the living will’s treatment instruction was moral.

If ACP fails, prolonged dying with suffering can result.

Still be Moral, How to gain approval:

Spend the required extra effort by attempting to prove this:

The intent of all concerned (patient during ACP, current treating physicians/providers, and others)

- Was not to hasten patient’s dying
- Was instead to solely relieve patient’s suffering

The Moral Principle of Double Effect

It is moral to commit an act if the intent is good,
Even if the outcome of bad is foreseen and possible,
As long as the bad outcome is not intended
And is not the means by which the good outcome is achieved.

So, if the physician’s intent and patient’s intent is to reduce suffering,
But there is a foreseen possibility that treatment will cause the patient to die sooner than if treatment is not provided,
The treatment is still considered moral.

For some terminal diseases, including advanced dementia, it’s not easy to die

Patients who have lost their ability to make treatment decisions, (decision-making capacity, or **DMC**), are particularly vulnerable. For advanced dementia, the percentage of patients who lose DMC approaches 100%, and can occur years before they die.

These patients **cannot**:

- Speak for themselves
- State what treatment they do or do not want now
- Revise their living will to make it current or effective
- Complete any aspect of advance care planning (**ACP**)

Other Terminal Illnesses Where Loss of Decision-Making Capacity is Important

- Cerebrovascular accidents (stokes)
- Persistent vegetative state
- End-stage renal disease
- End-stage liver disease
- Heart failure if severe
- High doses of opioid for pain (common in advanced cancer patients)

➔ **For convenience, “dementia” will be used in a generic way.**

The elusive holy grail of living wills

One essential characteristic of living wills
—ensuring goal-concordant, end-of-life care—
represents both their ultimate purpose
and their most formidable challenge.

This goal has proven so difficult to achieve that several leading experts in this field have publicly acknowledged abandoning pursuing this goal.

Instead, they recommend using living wills for other possible purposes,
or waiting for new tools to emerge.

More simply: Ideally,

Want = Get

Unfortunately, the other possibility is:

Want ≠ Get

Two trends are confusing:

Ability to diagnose dementia at onset and as the cause of death are getting better

Lifestyle changes and other factors are decreasing the rate of increase in dementia

Advanced dementia has limited options if your suffering is enough to want to be allowed to die

The **first limitation** applies to patients who do not depend on high-tech treatment to live. They have **No Plug to Pull.**

Traditional living wills that are silent regarding food and fluid:

- May allow dying to be prolonged for years
- May allow suffering to be prolonged for years

So, most “dementia-specific” living wills cease assisted feeding.

In this unique “dying” circumstance of life, feeding ≠ loving.

To be legal and moral, living wills should (but rarely) insist:

- Always offer food and fluid within reach
- Distinguish “offering” from “putting” food and fluid in the mouth
- Implement only if suffering is irreversible and severe
- Distinguish between relieving suffering and hastening death
- Argue that continuing feeding can be judged as being **unnatural**, **forced**, and **unethical** ➔

Forced Feeding Can Violate the Four Principles of Bioethics

- Respect patient’s autonomy
- Provide patient benefit
- Do No Harm to patient
- Distribute society’s limited resources fairly

Another limitation newly identified as important

The **second limitation** applies to patients who do not depend on others' assisting their feeding and hydrating. They retain this ability:

Some patients can still eat and drink independently
(in addition to having no plug to pull, and to being incapacitated).

To explain: the rate of progression of dementia causing loss of mental versus physical capacities varies greatly among patients.

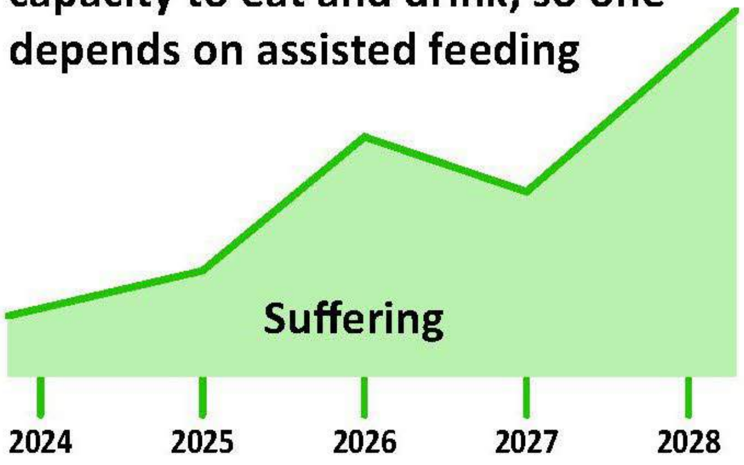
Patients who live in the Dementia Gap

A previously unidentified substage of dementia, in which patients:

- Lack capacity
- Do not depend on assisted feeding
- Want treatment to relieve exceedingly severe suffering despite risks
- My estimate for the number of Americans currently living in the Dementia Gap is 500,000.

The Dementia Gap

The time between having sufficient capacity to Voluntarily Stop Eating and Drinking (VSED)... and losing capacity to eat and drink, so one depends on assisted feeding



The Challenge is now well-defined: We need a Living Will that is effective, even for patients who livie in the Dementia Gap

But first, consider how successful “dementia-specific” living wills have been, in helping patients who do have one less challenge:
they depend on assisted feeding.

Are “Dementia-Specific” Living Wills Effective?

In 2022, BioMed Central published my critical review of new dementia-specific living wills, all of which had one or more of 24 identified flaws that could lead to premature or prolonged dying. This long article considers four types of flaws. Example: a living will intended for patients with early dementia required an ability to comprehend reading at grade 14 (second year of college).

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

My published critical review found most authors of living wills/advance directives completed only half the job: they included no strategies to compel physicians/providers to comply.

These authors stopped after helping patients create a clear form that could be notarized.

NO LIVING WILL was designed to help Dementia Gap patients. (Back then, neither did my living will.)

The Natural Dying Living Will:

- In continual development since 2006
- Illustrated since 2009 by collaborating with William Young
- Comprehensible at third grade reading level
- Content validity improved
- Free “Demo” online program is available

“In the illustrations, “P” means published; and
“S” means was or will be submitted for publication.

I do not use bathrooms so my clothes get wet and dirty. I depend on others to change my soiled diapers (nappies).

Purposes of illustrations:

- Clarification, easier to understand, improved content validity
- Added specific clinical detail for some conditions
- Depicted typical emotional responses of patients and family
- May importantly resonate with planning principals’ emotions
- Common ground if future translations used

Line drawings resulted from my collaboration with illustrator William Young at illooart@gmail.com and www.qucdrw.com.

Introducing a living will that is designed to help reduce suffering for all patients, including those living in the Dementia Gap

I have been extensively revising this living will for two years.

*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)

Caring Advocates' **Natural Dying Living Will** Now Offers **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. (Work began in 2006)

The protocol requires always placing food and fluid within your reach—to uphold the highest legal, ethical, and moral standards.

Since food and fluid is always offered, the goal is not to hasten dying. Arguable, patient died of his/her underlying disease.

The other treatment of last resort

Moderate Anesthesia (MA) provides you sedation to unconsciousness if (A) you are living in the “Dementia Gap” and (B) your exceedingly severe suffering (C) cannot be relieved by non-sedating treatment.

The protocol includes stopping sedating medications after about four days rest so your physician can ask, “Has your rest restored enough strength, so you now want to resume conscious living?”

Adding “Respite Sedation” to the protocol helps prove that your intent, and your physician’s intent was to relieve suffering—not hasten death. This and more (including its extensive informed consent) distinguish **MA** from the frequently used term, palliative sedation to unconsciousness.

Natural Dying Living Will now offers the treatment option of sedation

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

*Terman SA. Relieving Refractory Suffering in Advanced Dementia with a Protocol for Advance Care Planning, or a Protocol for Late-Stage Patients who Lack Directives—which can be Effective, Legal, and Moral

(*Work in progress)

Examples of My Way Cards

To exemplify a range of severity of suffering,

Here are a few examples of the living will ‘s patient decision aid that includes 50 My Way Cards, each of which depicts a specific clinical condition, in order of increasing severity:

No / minimal suffering
Tolerable suffering
Severe suffering
Exceedingly severe suffering

The task of advance care planning:
For each of the living will’s 50 conditions, **judge** how much suffering it would cause.

Based on this judgment, **decide** which POLST level of treatment you would want—if someday, you reached this condition.

(Later in the process of ACP, you will consider a way to handle more than one condition at a time.)

You have four levels of treatment to decide on:

- **CPRL** if the condition would cause **mild or no suffering**. (SLT + 1 CPR) since you still have dementia and need assisted feeding
- **Limited Treatment** (**SLT**) if it would cause **tolerable suffering (always DNR)**.
- **Natural Dying** (**ND**) if it would cause **severe suffering** (because medical dehydration is a peaceful way to die)
- **Moderate Anesthesia** (**MA**) if it would cause **exceedingly severe suffering** (so you will not be aware of your suffering)

Severe enough suffering

No suffering

P

I cannot use my own hands to put food and liquid into my mouth. So, to keep me alive, another person's hands must spoon-feed me, but I enjoy being fed.

P

I usually forget to swallow so food stays in my mouth. . .
I do NOT want puree placed at the back of my tongue to get me to swallow by REFLEX. [8.3]

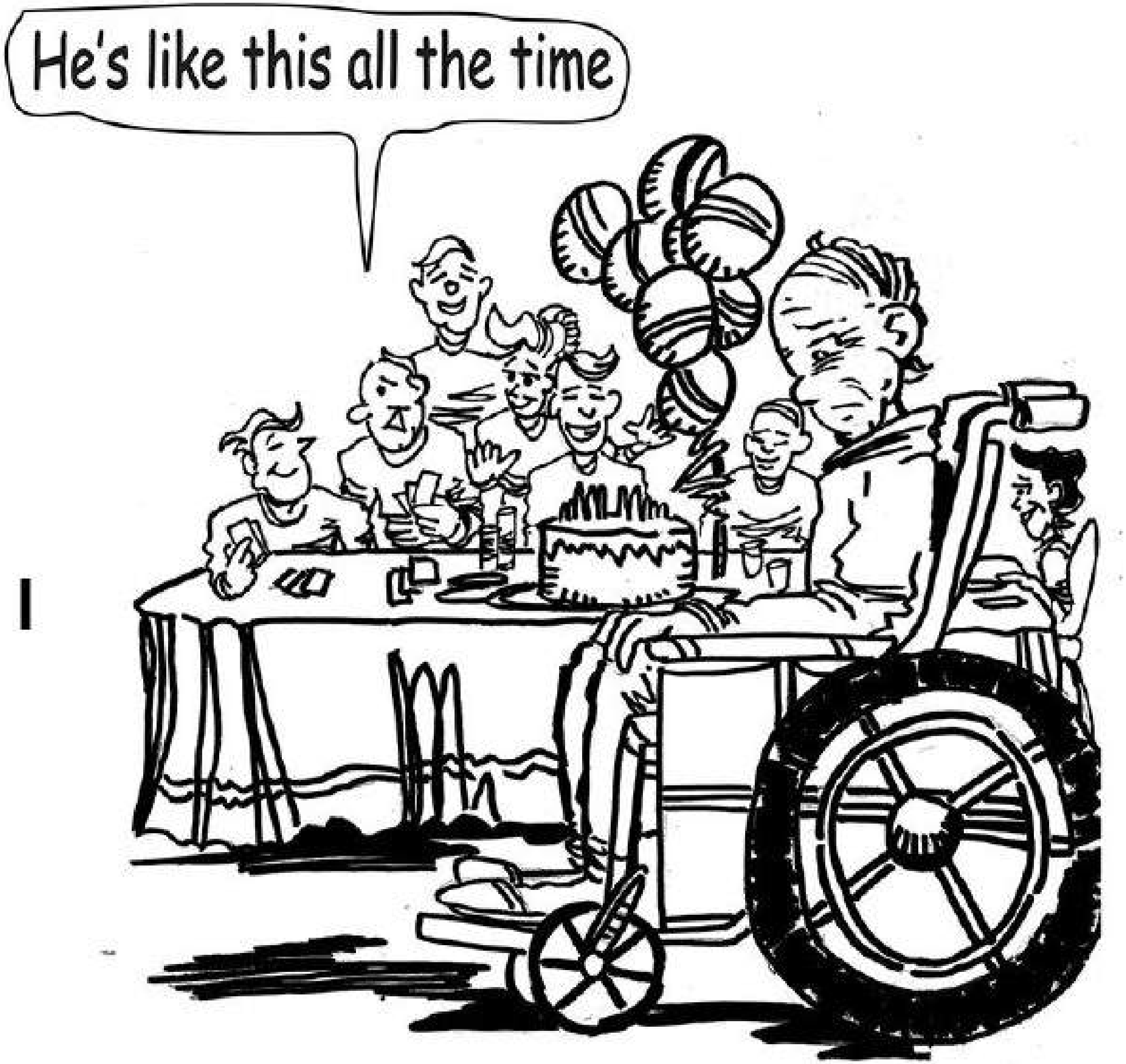
P

My family members' grieving goes on and on. My dying is taking a very long time because others insist on certain treatments. While my body looks like me, my mind has changed. I am very different from the person I used to be.

S

I just sit by myself. I look sad or have no emotion. I have no interest or energy to share with others so I cannot enjoy them.

S



So I do not hurt others or myself, doctors must give me a lot of medicine. This way, they will not need to tie me down. Otherwise if I get angry, I may hit people — even loved ones and others who are nice to me. [5.6]

SUCCESS in ADVANCE CARE PLANNING:

Your future treating physician/provider promptly implements the instructions for treatment that you previously had expressed—without conflict.

This requires additional effort in ACP ➔

Strategic Advance Care Planning's "DDDD"

- Demonstrate: memorialize wishes on video; swear a notarial jurat
- Diligent: consider your judgments of severity of suffering 3-6 times—and based them on your lifelong values and treatment choices
- Deliberative: discuss your decisions with physicians, ACP counselor, others; hold a final "Deliberative Capstone Review"
- Decision-making process and implementing strategies inspire your feeling confident about controlling (as much as possible) when and how you will have a peaceful and timely dying

Strategic Advance Care Planning requires completing Four Documents. Most are recorded on video. All are notarized by jurat:

1. Natural Dying Living Will
2. Bilateral durable power of attorney for healthcare decisions
3. Natural Dying Agreement
4. Series of completed “Future” POLSTs

A “Dear Doctor” WARNING: Why you should honor my Natural Dying Living Will.

Dear Doctor:

There are **three legal risks** if you fail to write orders that comply with my expressed, known wishes in this living will: The first is **criminal**. Providing treatment without consent is **battery**. The second is **civil**. Providing treatment without consent is a tort (**malpractice**). The third is **administrative (disciplinary)**. Sanctions or other adverse actions could be taken against your medical or professional license for unprofessional behavior.

Bilateral durable power of attorney excerpt:

I _______________ <agent> promise to advocate <patient>’s wishes expressed when they possessed capacity—even if it now seems against the apparent desires they are now expressing without capacity. Example: their physician implements the order to **“Cease Assisted Feeding” (Natural Dying)** based on their reaching a condition they judged (during ACP) would cause irreversible **severe suffering**, but now they grunt or mumble to indicate they want such assistance **to continue**…Below, both <patient> and I signed that we agreed to include this irrevocable (**Ulysses**) clause in this Bilateral Durable POA:

Natural Dying Agreement—Table of Contents

Two protocols for two types of patients

Strategic Advance Care Planning is for people who have capacity.

Advantages: Patient can, on video, try to passionately persuade future physicians to comply; express nuances about end-of-life wishes; and all strategies are available.

NOW Care Planning is for patients who lack capacity and already reached an advanced stage of dementia, but did not complete an effective living will. Advantages: some strategies are available, which may suffice. And is likely the best legal, ethical, and moral approach possible.

Two Protocols ask slightly different questions:

For **Strategic Advance Care Planning**, the repeating question is:
"How much suffering do *you* judge this condition would cause you or your family members?" (There are 50 conditions)

For **NOW Care Planning**, the repeating question is:
"How much suffering would <patient> have judged this condition would cause him/her and family members —if asked before losing capacity?" (To complete this task, they use their substituted judgment (as explained) and their extensive knowledge of <patient>.)

Example of Patient Decision Committee voting results that conditions of severe suffering are exceedingly severe

Each decision-maker was asked to use their substituted judgment to opine: "If the capacitated AK of the past had been asked, would she have judged any of these conditions are NOW causing exceedingly severe suffering—which qualifies her for Moderate Anesthesia?						
Summary (Conditions' exact wordings are listed below)	Husband/ agent	Caregiver	PDC 1*	PDC 2*	PDC 3*	Treating Physician
1.5 Lacks social judgment	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
2.1 Cannot use words meaningfully	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
2.2 Cannot indicate Yes or No	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
3.2 *Existential suffering**	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
4.4 Fights caregivers	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
4.6 Embarrassing actions	**Y**					
5.2 Cannot socialize/enjoy family	**Y**					
5.3 Agitation		**Y**				
5.6 Angry, hits people	**Y**	**Y**				
6.3 Treatment is futile						**Y**
7.6 Mind/body paradox harms others		**Y**				**Y**

Why “Future POLSTs” can be effective

- Immediately actionable (limits time for conflicts to emerge)
- Other providers required to follow “Providers’ Orders” by law
- Designed to apply regardless of treatment setting

Additional (unique) Strategies:

- Insists only patients can change POLST → durable
- Insists orders be consistent with Living Will → effective
- Patient Decision Committee authorizes current agent to request treating physician to implement the now clinically appropriate, previously completed POLST by accepting previous providers’ assessments of DMC, voluntariness, and no suspicion of undue influence (whose POLST Conversation was recorded on video).

VSED (Voluntarily Stopping Eating and Drinking) POLST using National POLST form

- Used as medical/legal "insurance" to prevent others who would—perhaps in good faith, but incorrectly—attempt to sabotage your end-of-life plan
- VSED cannot be chosen unless you still have capacity
- This POLST is an example of one of TEN Future POLSTs
- For any POLST where you lack capacity, your Patient Decision Committee will vote which one is clinically appropriate
- Reasons for using "National POLST" are explained elsewhere

HIPAA PERMITS DISCLOSURE OF POLST ORDERS TO HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

Medical Record # (Optional)

National POLST Form: A Portable Medical Order

Health care providers should complete this form only after a conversation with their patient or the patient's representative. The POLST decision-making process is for patients who are at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty (www.polst.org/guidance-appropriate-patients-pdf).

Patient Information. **Having a POLST form is always voluntary.** **VSED**

This is a medical order, not an advance directive. For information about POLST and to understand this document, visit: www.polst.org/form

Patient First Name:

Middle Name/Initial: Preferred [**gov. photo ID**] name, unless same:

Last Name: Suffix (Jr, Sr, etc):

Date of Birth (mm/dd/yyyy): State where form was completed:

Gender: Social Security Number's last 4 digits (optional): xxx-xx-

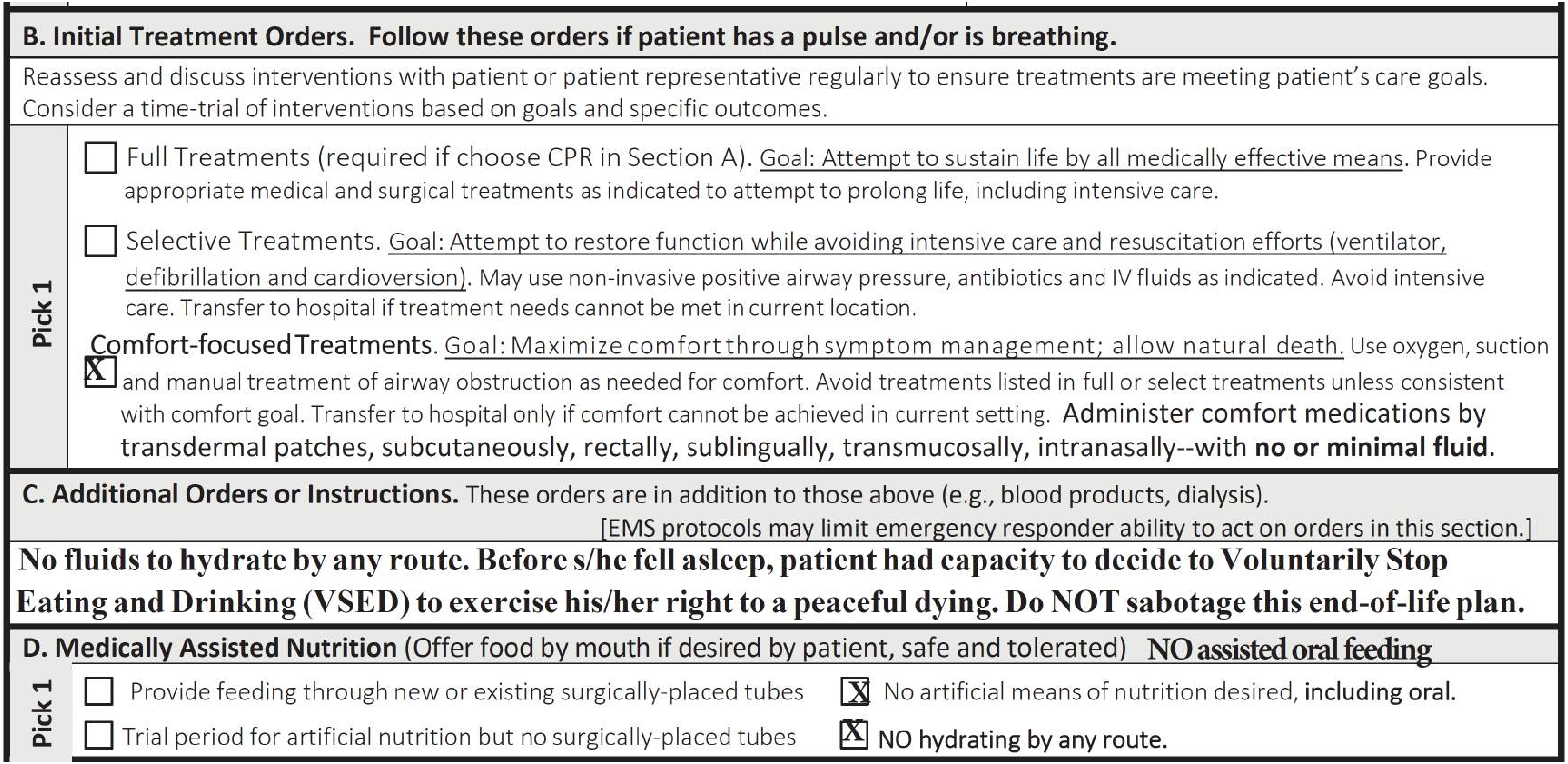
A. Cardiopulmonary Resuscitation Orders. Follow these orders if patient has no pulse and is not breathing.

Pick 1

☐ YES CPR: Attempt Resuscitation, including mechanical ventilation, defibrillation and cardioversion. (Requires choosing Full Treatments in Section B)

☒ NO CPR: Do Not Attempt Resuscitation. (May choose any option in Section B)

* * * **Do NOT START an IV** * * *



B. Initial Treatment Orders. Follow these orders if patient has a pulse and/or is breathing.

Reassess and discuss interventions with patient or patient representative regularly to ensure treatments are meeting patient's care goals. Consider a time-trial of interventions based on goals and specific outcomes.

Pick 1

☐ Full Treatments (required if choose CPR in Section A). Goal: Attempt to sustain life by all medically effective means. Provide appropriate medical and surgical treatments as indicated to attempt to prolong life, including intensive care.

☐ Selective Treatments. Goal: Attempt to restore function while avoiding intensive care and resuscitation efforts (ventilator, defibrillation and cardioversion). May use non-invasive positive airway pressure, antibiotics and IV fluids as indicated. Avoid intensive care. Transfer to hospital if treatment needs cannot be met in current location.

☒ Comfort-focused Treatments. Goal: Maximize comfort through symptom management; allow natural death. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Avoid treatments listed in full or select treatments unless consistent with comfort goal. Transfer to hospital only if comfort cannot be achieved in current setting. Administer comfort medications by transdermal patches, subcutaneously, rectally, sublingually, transmucosally, intranasally--with **no or minimal fluid.**

C. Additional Orders or Instructions. These orders are in addition to those above (e.g., blood products, dialysis).
[EMS protocols may limit emergency responder ability to act on orders in this section.]

No fluids to hydrate by any route. Before s/he fell asleep, patient had capacity to decide to Voluntarily Stop Eating and Drinking (VSED) to exercise his/her right to a peaceful dying. Do NOT sabotage this end-of-life plan.

D. Medically Assisted Nutrition (Offer food by mouth if desired by patient, safe and tolerated) **NO assisted oral feeding**

Pick 1

☐ Provide feeding through new or existing surgically-placed tubes	☒ No artificial means of nutrition desired, **including oral.**
☐ Trial period for artificial nutrition but no surgically-placed tubes	☒ NO hydrating by any route.

The last of Seven Steps to Strategic Advance Care Planning

1. Patient-family/Patient Decision Committee webinar: How the "Implementation Phase" is typically initiated
2. What if any signatures without a notary still need to be signed
3. Where will the documents and videos be stored and how will they be easily and readily retrieved
4. The minimum to present a future physician/provider?
5. The pros and cons of MAiD—which requires **DMC**
6. Questions and answers
7. How to refer others
8. Some suffering is hard to detect or inherently non-observable: see 30-second video reveals unrecognized but severe pain

My overall advice is embodied in this slogan:

Plan now, die later—to live longer

Stanley A. Terman, PhD, MD
Caring Advocates

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Final Points and Summary :

This is a HUGE challenge. I estimate between 1.5 and 2 million patients currently need, but do not have, an effective living will/advance directive to attain relief from severe suffering that is often not observable.

The estimated annual cost of care will soon exceed a trillion dollars a year but does not account for the human suffering of patients and their family members. One person's disease affects the lives of others, including family members who become caregivers by abandoning their professions to keep their relative alive who really would have wanted—perhaps years ago—to have a peaceful and timely dying.

A Huge Problem <move earlier>

- About 2 million (11% of those of 65) American live in advanced dementia <check, citation>

- One-third of people over 65 die with dementia

- “The lifetime risk of dementia after age 55 years was 42% [but…] substantially higher in women, Black adults and APOE ε4 carriers” (up to 60%). Fang M, Hu J, Weiss J, et al. Lifetime risk and projected burden of dementia. Nat Med. 2025 Jan 13. doi: 10.1038/s41591-024-03340-9

Stanley A Terman's selected articles (updated March 2025)

Notes: Recommended titles have an *****. Each article can be accessed on line by copying and pasting what follows the "DOI:", which always begins with "**10**".0
➔ Copy and paste this number (without a period) into your browser to access the article. Almost all are free ("open access") to read and download.
[Note: Below, brief annotations are in brackets like these.]

[Since this sequence of articles begins with the most recent, the (working) titles of two forthcoming articles begin this list. These penultimate drafts are available upon request.]

*Terman SA. Relieving Refractory Suffering in Advanced Dementia with a Protocol for Advance Care Planning, or a Protocol for Late-Stage Patients who Lack Directives—which can be Effective, Legal, and Moral (work in progress)

*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)

Terman SA, Steinberg KE, Pope TM. Letter response to Clifford et al. "Navigating late-stage dementia: A perspective from the Alzheimer's Association". Alzheimers Dement (Amst) 2024;16(4):e70014. DOI: 10.1002/dad2.70014

[Note: the two articles that Alzheimer's & Dementia published (a journal of the Alzheimer's Association), got the organization's attention and assigned three of its staff members to write an article to which my two colleagues and I responded by writing the above letter.]

*Terman SA. Can an effective end-of-life intervention for advanced dementia be viewed as moral? Alzheimers Dement (Amst) 2024;16(1):e12528. DOI: 10.1002/dad2.12528
[Note: This article was likely the more provocative article]

Terman SA, Steinberg KE. Responses to Open Peer Commentaries about "Timely dying in dementia: use patients' judgments and broaden the concept of suffering" and "Can an effective end-of-life intervention for advanced dementia be viewed as moral?". Alzheimers Dement (Amst) 2024;16(1):e12529. DOI: 10.1002/dad2.12529
[Note: The article type was *Perspectives*, which invites others' Open Peer Review, and then my responses.]

*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):e12527. DOI: 10.1002/dad2.12527

[Note: Several of my articles share this goal: to make all aware of how much patients living with advanced dementia could be suffering. The Open Peer Commentaries and responses for this article are combined with the other, above.]

Terman SA, Steinberg KE, Hinerman N. Correction to: 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):111. DOI: 10.1186/s12910-022-00850-4 [Note: minor change]

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

[Note: This 2022 article does *not* critique the "My Way Cards" patient decision aid, which is instead, the subject of a forthcoming article)]

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):e1-e2. DOI: 10.1016/j.jamda.2019.04.010

[Note: the first of several articles that eventually led to a leading national organization's decision to reverse their over-reaching, paternalistic policy to refuse to honor advance directives for late-stage dementia.]

Mirarchi F, Cammarata C, Cooney TE, Juhasz K, Terman SA. TRIAD IX: Can a Patient Testimonial Safely Help Ensure Prehospital Appropriate Critical Versus End-of-Life Care? J Patient Saf 2021;17(6):458-466. DOI: 10.1097/PTS.0000000000000387
[Note: see below]

Mirarchi FL, Cooney TE, Venkat A, Wang D, Pope TM, Fant AL, Terman SA, Klauer KM, Williams-Murphy M, Gisondi MA, Clemency B, Doshi AA, Siegel M, Kraemer MS, Aberger K, Harman S, Ahuja N, Carlson JN, Milliron ML, Hart KK, Gilbertson CD, Wilson JW, Mueller L, Brown L, Gordon BD. TRIAD VIII: Nationwide Multicenter Evaluation to Determine Whether Patient Video Testimonials Can Safely Help Ensure Appropriate Critical Versus End-of-Life Care. J Patient Saf 2017;13(2):51-61. DOI: 10.1097/PTS.0000000000000357
[Note: The above two articles established the basis for adopting the protocol to record patient's capacitated instructions for EMTs/first responders' greater accuracy.]

Terman SA. To Live Long Enough to Warm the Hearts of Others: Reflections on Informing my Patient about a Peaceful Way to Die. Narrat Inq Bioeth 2016;6(2):102-105. DOI: 10.1353/nib.2016.0004

Terman SA. Let Medicare Pay Physicians for Advance Care Planning. Don't Revive the "Death Panel" Theory. J Am Geriatr Soc 2016;64(4):919-20. DOI: 10.1111/jgs.14045
Terman SA. Is the principle of proportionality sufficient to guide physicians' decisions regarding withholding/withdrawing life-sustaining treatment after suicide attempts? Am J Bioeth 2013;13(3):22-4. DOI: 10.1080/15265161.2013.760967

Terman SA. It Isn't Easy Being Pink: Potential Problems with POLST Paradigm Forms. Hamline Law Review 2013;66(1):1-15.

Terman SA. Peaceful Transitions: Plan Now, Die Later—Ironclad Strategy. Carlsbad (CA): Life Transitions Publications; 2011.

Terman SA. The BEST WAY to Say Goodbye: A Legal Peaceful Choice at the End of Life. Carlsbad (CA): Life Transitions Publications; 2007.

Terman SA. Determining the decision-making capacity of a patient who refused food and water. Palliat Med 2001;15(1):55-60. DOI: 10.1191/026921601672818272

Other preprints posted on SSRN:

The theme: "*TIMELY DYING IN DEMENTIA is the thematic supra-title for most of my articles that focus on advance care planning (ACP) for any terminal illness, esp. advanced dementia. Success allows patients to avoid prolonged dying with suffering. The series begins with two reviews that convincingly conclude: 1) most advance directives for dementia are flawed, and 2) surrogates' substituted judgment is not reliable. A possible solution: 3) use irreversible, severe suffering as the sole, compelling criterion for when to die; 4) use arguments to overcome moral resistance to the order, "Cease oral assisted feeding"; 5) use an illustrated, easy-to-read, comprehensive directive; 6) during ACP, complete "Future POLSTs," which are binding documents; 7) add strategies to make advance treatment requests irrevocable; and 8) add verifying security -- to attain end-of-life, goal-concordant care.*"

Timely Dying in Dementia: An Evolving, Binding, Irrevocable Contract to Persuade Physicians to Honor Advance Directives that Request Cessation of Assisted Oral Feeding
Number of pages: 47 Posted: 29 Nov 2022
Stanley Terman
Caring Advocates or Institute for Strategic Change
Downloads45(849,773)
View PDF
Download

Timely Dying in Dementia: An Illustrated, Easy-To-Complete, Comprehensive Living Will
Number of pages: 37 Posted: 09 Feb 2024 Last Revised: 25 Mar 2024
Stanley Terman
Caring Advocates or Institute for Strategic Change

Downloads34(948,054)
Citation1
View PDF
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(This is the former draft of “Relieving Refractory Suffering…” for those interested in comparing the two.)

To Prevent Harm Caused by Fraud in Advance Directives, and to Persuade Providers to Honor Requests to Cease Assisted Feeding for Patients Living with Advanced Dementia: Add Advanced Security Technology to Future POLSTs
Number of pages: 34 Posted: 23 Dec 2022
Stanley Terman
Caring Advocates or Institute for Strategic Change
Downloads25(1,044,807)
View PDF
Download

Seven Steps to Strategic Advance Care Planning

Why: Imagine receiving well-meaning but unwanted treatment that maintains your existence in an advanced stage of dementia—while you cannot articulate that your suffering is so severe, so difficult to detect, and so challenging to treat—that you prefer to be allowed to die. Further imagine that you currently do not know how, or are incapable of expressing your wish, to end your torment. Or, if you would consider stopping your intake of food and fluid, or receiving enough sedation to end your suffering, you would not know how to convince your future physicians/providers to comply with your wishes if they considered these treatments controversial based on their possibly hastening your dying.

Dedicated healthcare providers may not be able to observe some sources of your suffering because your pain is not detectable, your disease is causing your loved ones to suffer, and/or your suffering will occur in your future. One example is leaving your survivors tarnished memories of yourself. Those who observe you in an advanced stage of dementia may conclude, “You are just sitting there,” but your existential suffering from losing important relationships has left you socially isolated and terribly lonely—after dementia has destroyed your sense of your own identity, your ability to recognize and communicate with others, and made you incapable of recalling and sharing past experiences.

The number of persons now living in advanced dementia (PLADs) is likely over two million in the US, and will likely double by 2050. While no one knows the precise percentage of patients whose suffering is severe, estimates are arguably between 25% to 50%. Caring for these patients can be physically, emotionally, and financially burdensome to patients’ family, friends, and society. The cost of care can climb to $125,000 annually. Some patients may live a decade. For those over 65, the risk of getting dementia doubles every five years; almost 10% have dementia; and one-third will die with dementia.

While assessing the intensity of your current suffering is elusive since many sources are non-observable, you can take effective action by planning ahead; that is, by completing **Strategic Advance Care Planning**. This protocol begins by asking you to judge 50 specific clinical conditions that you might someday reach. Your judgments for each condition’s potential to cause future suffering can then be based on your lifelong values and treatment preferences.

When: You must complete Strategic Advance Care Planning (**Strategic ACP, SCAP**) while you still have decision-making capacity (**DMC**). DMC is the mental ability to perform the specific task of making conditional advance treatment decisions. “Conditional” means you have reached an observable future clinical "qualifying" condition. The premise that underlies this approach is that clinical conditions can be observed, but how much suffering they may cause is up to you to judge. DMC requires your ability to understand the treatment options, appreciate each option's likely consequences, use rational thinking to render a diligent, deliberative decision, and to express this decision consistently over time. One advantage of Caring Advocates' "**My Way Cards**" online program that generates your "**Natural Dying Living Will**" is that each of its 50 conditions is illustrated and written at the third-grade level of reading ability.[1] Lowering the comprehensive level to complete this task makes it possible for many patients in early dementia to have sufficient DMC to complete their Natural Dying Living Will. Note: you can lose your DMC in ways other than dementia such as head trauma due to a car accident, a stroke, end-stage kidney or liver disease, other neurodegenerative diseases, and side-effects from medications, including pain relieving medications. You must complete DMC before any of these occur, so don't delay in completing Strategic Advance Care Planning.

Who: Caring Advocates is a not-for-profit organization founded by, and continuously led by bioethicist/psychiatrist Stanley A. Terman, Ph.D., M.D., since 2000.[2] The protocol, Strategic Advance Care Planning, is designed for people who want to **control how and when they die** (as much as feasible). Unlike other protocols, SACP does not stop after helping patients complete a comprehensive, clear and convincing, living will that states what treatments patients **want** if they reach a specific condition. (Note: "clear and convincing" is the highest standard of evidence in civil legal matters.) SACP adds layers of strategies to make success likely, where success is defined as patients **receive** the treatment they want. The Caring Advocates team can work with hospice if its medical and administrative leaders agree with the treatment that your Natural Dying Living Will instructed, although some authorities consider **Natural Dying** and **Moderate Anesthesia** controversial. If so, Caring Advocates may still be able to help without hospice. It depends on the specific circumstances that can be discussed.

How: Strategic Advance Care Planning has two parts: Planning and Implementation. You can create a plan *now* that is designed to be straightforward to implement *later*—even if Dr. Terman is not available. To explain: You can have a **POLST** Conversation with Dr. Terman, who will determine that you have DMC and share an adequate amount of information with you. Then, you can give your informed consent by signing/completing each **POLST** that contains medical orders written by Dr. Terman to fulfill your end-of-life goals. Example: you want to avoid a prolonged dying with suffering, and you want to live as long as you can still enjoy life, so you do not want your dying to be premature.

Each **POLST** is a set of specific immediately actionable physician orders that other healthcare providers are required to honor in all settings—including your home, hospital, skilled nursing facility, or luxury hotel to which you may move if comfort care cannot be obtained in your current residential setting. There are two exceptions to requiring other healthcare providers to honor your **POLSTs**, but they are infrequent. Both can be worked around. (A) Providers and institutions are required to reveal if they have a moral conflict with any intervention so that proxies/agents can seek treatment from other healthcare providers and institutions to provide the care that you desire. (B) Providers who claim the intervention requested is not consistent with generally accepted medical care must do so *in good faith*. Your proxy/agent may petition a court of law to prove this, and if they fail, they risk losing their legal immunity. Most importantly, your **POLST** and your **Natural Dying Living Will** can work together if you follow the recommendation of adding this order to each POLST: “POLST orders must be consistent with the patient’s directive (living will).”

Completing POLSTs requires four tasks. Dr. Terman and his staff routinely complete the first three:

1. Dr. Terman or his staff can facilitate your deciding and memorializing which category of treatment you want upon reaching specific future clinical (qualifying) conditions. This task uses the online program of My Way Cards to generate a Natural Dying Living Will.
2. Dr. Terman can, during the POLST Conversation, provide adequate information and determine if you have sufficient decision-making capacity to sign POLSTs whose orders could be life-determining.
3. Dr. Terman can write orders on POLST forms, so you can receive goal-concordant care. *Note that tasks 1 to 3 can be completed during advance care planning.*
4. If someday, you reach a “qualifying condition,” any physician/provider can implement the orders on these POLSTs, as explained below.

To explain: The usual and customary practice of medicine includes asking a currently treating physician to rely on the assessment and to carry out the orders that a previous physician wrote—if the patient’s clinical condition warrants these orders. While the needed orders may be legal, clinically appropriate, and moral, some physicians will still consider them controversial. If the currently treating physician refuses to implement a POLST, the proxy/agent must search for another physician who is willing. Since sabotage is possible after these orders are written, SACP also includes additional strategies designed to overcome them. An example: after you become an incapacitated person currently living with advanced dementia you may still request assisted feeding and hydrating even though you have reached a qualifying condition as expressed stated in your Natural Dying Living Will. Strategic Advance Care Planning accepts this widely accepted clinical fact: It is difficult to contemporaneously assess how much suffering a person living with advanced dementia (PLAD) is experiencing. To overcome this challenge, the SACP protocol includes a unique collaboration between the competent patient who completes advance care planning (planning principal) and their future treating physician. Physicians can focus on a PLAD's current condition as they ask: "Has my patient reached any condition that, as a planning principal they previously judged would cause irreversible severe suffering; that is, has my patient reached a 'qualify condition' as defined in their Natural Dying Living Will?" If so, their living will must spring into action by implementing a previously completed POLST that can include such orders as "Cease assistance by another person's hand with oral feeding and hydrating" upon which the patient's survival depends[3]; that is, stop putting food and fluid in the patient's mouth. Terman's article explained why this treatment is arguably moral.[4] Another example, which requires suffering be exceedingly severe and two qualifying conditions can work for patients who can still eat and drink independently: increase the dose of sedating medications until the symptoms of suffering are adequately treated or the patient's mind is dissociated from experiencing exceedingly severe suffering. This treatment is called Adequate or Moderate Anesthesia. This intervention requires your informed consent after you are adequately informed about its benefits and risks that include this possibility: You might not regain consciousness before you die.

The clinical interventions that Strategic Advance Care Planning recommends strive to be both effective and acceptable to people with a wide range of beliefs and values: from traditional moralists who abhor any intervention intended to hasten dying, to activists who advocate their own and others' right-to-die. Acceptance is required to implement the treatment needed, to prevent forcing vulnerable patients to endure prolonged dying with irreversible severe, or exceedingly severe suffering. Ideally, patients given the diagnosis of dementia will be able to enjoy life as long as possible, and then experience a private, peaceful, and timely dying. "Timely" means dying will be neither prolonged nor premature based on the patient's preferences.

History: Caring Advocates has been offering and continuously improving its strategic protocol for two decades—by integrating the input shared by professionals in the disciplines of medicine, law, bioethics, Alzheimer's and related dementia, end-of-life conflicts, hospice and palliative care, and religion, as well as incorporating feedback from patients as they completed the SACP protocol.

Unique aspects of the SACP protocol: Examples: (A) Each of the 50 **My Way Cards** was subjected to dozens of interviews that asked patients to describe what they understood as the considered condition. This process improved **content validity**, which is needed so all concerned know they are judging and acting on the same condition. (B) Advance care planning counseling providers always engage with patients as they strive to make advance treatment decisions that are consistent with their lifelong values and treatment preferences.[2] While the time required to complete SACP is several hours of effort (compared to several minutes for other protocols), the protocol gives planning principals the opportunity to demonstrate that they had DMC as they made each of 50 advance treatment decisions in a diligent, deliberative, consistent way.

Benefits: Confidence that your completed plan **will control when and how you will die** can reduce your **Dementia Fear**. This fear includes anxiety and worry about whether you can control your fate and avoid "getting stuck" in an advanced stage of dementia for a long time. Sadly, the Dementia Fear leads some patients to consider, and worse leads some to act, by ending their lives. Premature dying has a high cost. It sacrifices an unknown number of years of fulfilling living, for you and your family, since many middle-stage dementia can still enjoy life despite their incapacity.

To facilitate attaining **goal-concordant care**, complete the **Seven Steps** described below that includes a set of documents and videos designed to **inform** and help your proxy/agent/surrogate (**agent**) persuade your future physicians to honor your end-of-life wishes. Many patients feel peace upon completing their plan based on knowing they put in the extra effort that may be required to overcome future challenges of advanced dementia and other terminal illnesses.

Summary: For two decades, Caring Advocates has continually improved Strategic Advance Care Planning. We are dedicated to avoiding premature as well as prolonged dying for any terminal illness. We believe that following our protocol can be effective when needed, so that this goal is possible:

Plan Now to Die Later®—to Live Longer.

* * *

The Seven Steps of ACP are organized into three groups:

OVERVIEW:

- **Steps 1 to 4** facilitate your deciding, expressing, and memorializing **what** treatment you do or do not want, and **when**, if you lose your ability to make treatment decisions for yourself,[1] which begins below. It includes a diligent , paragraph-by-paragraph final review of your Natural Dying Living Will in collaboration with your ACP counselor that can use sharing the Word document onscreen as final changes are personalized. This video-recorded event is called **Deliberative Capstone Review** (**DCR**).

- **Step 5** adds strategies to motivate your future physician to implement the orders you need. Strategies also can prevent others from sabotaging the orders they write. (This step begins on Page 13.)

- **Step 6** actualizes your expressed wishes by turning them into **POLSTs** (Physician/Portable Orders for Life-Sustaining Treatment) that have the **power of physicians' orders** that the laws in most state laws **compel** other healthcare providers **to honor** (with few exceptions).

- **Step 7** begins after you complete all your documents and videos. This step offers you options regarding the storing, carrying, and wearing your POLSTs as well as ways to provide quick access to these documents and videos so all concerned can learn which **POLST** should be currently implemented so that, for the last chapter of your life, you can attain goal-concordant care.

  Step 7 also offers a "Patient Decision Committee—Patient" webinar on Zoom with the ACP Counselor, where all concerned—especially those new to the process, such as your proxies/agents—can benefit from an overview of the completed work, can ask questions about any step, and can learn the typical ways in which treatments of last resort are implemented; in other words, to answer the question, "What are the likely course of events when 'that time' comes?"

  Finally, you may wish to complete an "Ethical Will" in which you can state to your survivors what values you found important in your life and you would like them to continue.

Step 1: Complete your initial Natural Dying Living Will

How it Works

Step 1 uses **My Way Cards**, an online, illustrated patient-decision aid, to generate your Natural Dying Living Will. [1] Each of the 50 cards illustrates and describes one end-of-life or advanced-dementia condition written at the third-grade level of reading comprehension. Together, these conditions strive to reflect all of what people dread most about being forced to endure prolonged dying in advanced dementia and other terminal illnesses. The descriptions are behavioral, not diagnostic. For example, if you cannot move your body irreversibly, even to say hello, how much difference does it make if you are living in an advanced stage of dementia, a persistent vegetative state, had a stroke, or living with ALS (Lou Gehrig's disease)? Using behavioral criteria reduces potential conflict over the correct diagnosis and reflects what people care about most: losses of functioning and unwanted, embarrassing behaviors. The two most important questions are not about diagnosis. Instead, they are: Is your condition irreversible? And, will it cause you and/or your loved ones to experience severe suffering?

You can complete the **My Way Cards** program using your computer, tablet, or cellphone. (A printed version is available for those with special needs.) For each condition, you will be asked:

> Based on your lifelong values and treatment preferences, do you judge this condition will, by itself, cause severe enough suffering to want to be allowed to die of your underlying disease?

If your answer is, "No or mild suffering, which is not enough," then you may decide you want to receive cardiopulmonary resuscitation (**CPR**) with Full Treatment, or **DNR** but Full Treatment otherwise. Another option, if you depend on a caregiver to hand feed and hydrate you, and you still enjoy living, is to choose only one Full CPR attempt, which—if successful—will be followed by Selective/Limited Treatment that refuses burdensome, invasive treatments (**CPRL**).

If you judge a condition would cause **severe** suffering, you can express your instruction for your future physician to implement the orders for **Natural Dying** (**ND**). These orders can be clinically effective to allow you to have a timely dying even if you have "No Plug to Pull"; that is, if your life can be sustained without any medical treatment since you only need food and fluid to live. In contrast to some living wills, the Natural Dying Living Will does not demand withholding of food and fluid. This can be criticized as euthanasia and illegal. Instead, it **withdraws assistance with assisted oral**

feeding and hydrating by caregivers' hands. The two orders for **Natural Dying** are:

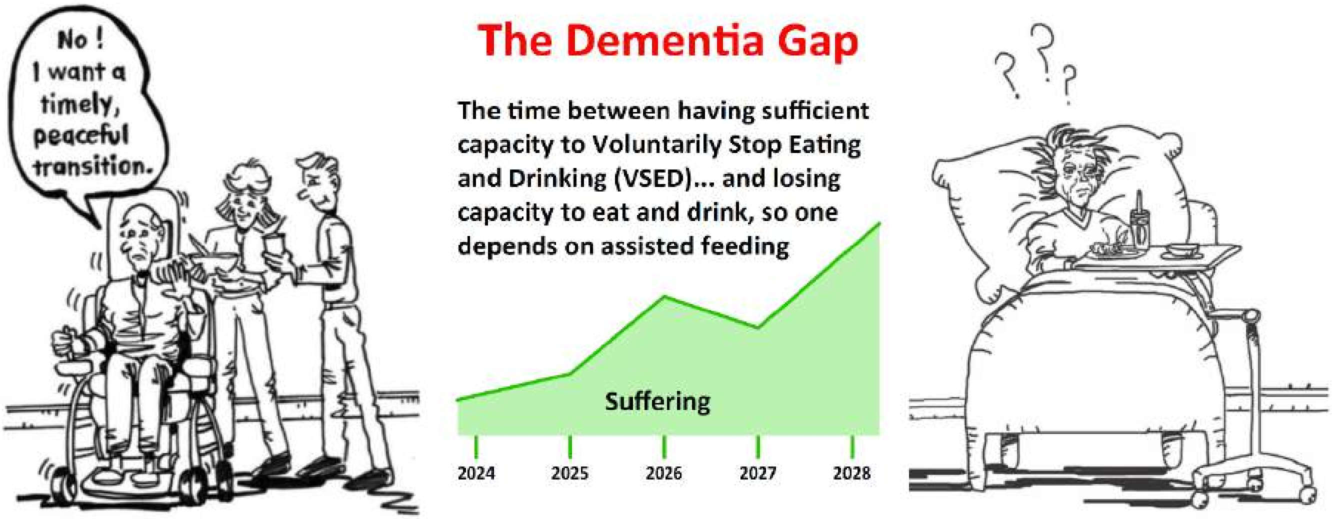
(1) "Cease assisted oral feeding" and
(2) "Always place food and fluid within the patient's reach."

The Natural Dying Living Will strives to be both **effective and acceptable**. To this end, Terman published an article that argued why **Natural Dying** is moral.[4]

(Optional reading:) Using the criterion, "How much suffering would the condition cause?" is more compelling and specific than criteria included in most traditional and the new crop of "dementia directives." [5] For example, the instruction to forgo treatment, "If the harms and burdens of treatment outweigh its benefits," is a laudable goal in theory, but in practice is usually too vague. Judging that your "Quality of Life" is too low, or that your "indignity" is too high, are also vague. Worse, such questions could lead to judging the lives of others are not worth living, which could start a dangerous slippery slope.

Other living wills use a substage of the Functional Assessment Staging Tool (**FAST** scale), but this approach to timing has an underappreciated problem: **FAST** is a research tool; it was not designed for making end-of-life treatment decisions. More generally, a living will whose criteria are based on reaching clinical conditions may be flawed and lead to premature dying. For example, it would be premature to allow you to die once you no longer can recognize your close family members," since you and they may still enjoy spending time with each other. [3] A 2022 critical review of a new crop of dementia-specific directives revealed all had at least one flaw that could lead to either premature or prolonged dying. [5]

Many patients have a great but relatively unappreciated challenge: They live in the **Dementia Gap**. While their suffering is exceedingly severe suffering, they can still eat and drink independently, so they **cannot** rely on an advance decision to refuse **assisted** oral feeding and hydrating (**Natural Dying**). To respond to this important patient need, another intervention was developed in 2023. [Terman, SA. Timely dying in dementia: To overcome the **Dementia Gap**, can **Moderate Anesthesia** be viewed as moral? (Manuscript in preparation.)]



The Dementia Gap

The time between having sufficient capacity to Voluntarily Stop Eating and Drinking (VSED)... and losing capacity to eat and drink, so one depends on assisted feeding

The **Dementia Gap** is a period of time. It **begins** with patients' loss of capacity to exercise their legal right to refuse all food and fluid; that is, to Voluntarily Stop Eating and Drinking. The **Dementia Gap ends** when, due to the progression of their dementia, patients lose their ability to eat and drink and depend on assistance from caregivers, so they finally qualify for **Natural Dying**. Little is known about the prevalence, or average and range of duration **Dementia Gap**. No guidelines are available to help physicians estimate how long their patients may remain in this state. But experience has shown that loved ones of patients living in the **Dementia Gap** may need additional, proactive grief counseling.

Patients can choose to receive **Moderate Anesthesia** (**MA**) in advance, if they are in the **Dementia Gap** and have reached two or more conditions previously judged as causing **exceedingly severe suffering**. The level of sedation in **MA** is similar to that induced during endoscopy: a very deep sleep, so you do not respond purposefully to moderately loud verbal commands or to moderate tactile stimulation, but you do withdraw from painful stimuli, and you can breathe on your own without a respirator. Usually, medications do not need to be given by I.V. The

Moderate Anesthesia is a new and purely clinical term, that I prefer to similar terms such as palliative sedation **to** unconsciousness, or terminal sedation, since it does not open the door to criticism that the treating physician's intent was to hasten dying. Yet **MA** can be your "intervention of last resort" if no other less sedating way can reduce your exceedingly severe suffering and you can still eat and drink without help.

Your physician's intent in inducing **MA** can be either to reduce the source of your suffering, or to decrease your awareness of suffering. The first has a possible and foreseen, but unintended side-effect: it may render you unconscious, and end your life earlier. The Rule of Double Effect may morally justify **MA** if your physician intended only the "good" effect (to reduce your suffering) but did not intend to use the possible "bad" effect (causing you to die) as the means to reduce your suffering.

Physicians may also intend to deliberately reduce your consciousness by slowly increasing the dose of sedating medications until you are no longer aware of your suffering.

To help prove that your physician's intent is to reduce your experience of suffering but not cause your earlier death, you can consent to the "Respite Sedation" protocol; that is, you can agree to have your medications reduced or stopped so you wake up after about four days. Then, your physician can ask you, "Has this rest allowed you to regain enough strength, so you want to continue to live and be awake?" (Note: this part of the protocol **cannot** apply to **PLADs** since they will have lacked decision-making capacity before sedation so they will predictably not be able to answer this question.)

Benefits of My Way Cards

- **Educates** you about what it can be like, for you and your loved ones, to live with advanced dementia and other terminal illnesses with both illustrated cards and online videos.
- **Facilitates** your making a clear and specific advance treatment decision for each condition, so you can express **what** intervention you want and **when**, based on your lifelong values.
- **Memorializes** your wishes in print, to inform your future physicians and others.
- **Reduces** your agent's emotional burden since they will be following your decisions, not making life-or-death decisions on your behalf. Your agent's main role is to serve as your advocate by persuading your future treating physician and others to honor the treatment decisions that you previously made. Note: Agents will only be asked to exercise their "substituted judgment," which is their traditional role, to make the same decision you would have made, if your living will omitted the condition you reached or the decision you expressed is unclear.

Why this Step is Unique

The online program uses 50 My Way Cards to generate your Natural Dying Living Will. It strives to be comprehensive so it can be your only living will. (It is not merely an addendum.) Since the descriptions of the conditions are illustrated and written at the third-grade level of reading comprehension, early-stage dementia patients and others with diminished cognitive functioning may be able to use complete it to express their end-of-life wishes.

Definition of the broadened concept of suffering

The broadened concept of suffering includes sources that cannot be detected by observing the patient that includes: 1) physical pain that physicians and others may not detect; 2) emotional or psychic suffering—especially in patients who are withdrawn; 3) existential suffering such as loss of meaning in life, fear of dying, and near total social isolation due to losing the abilities to (a) communicate, (b) recognize loved ones, and (c) recall significant life events; 4) disruption of life narrative, such as one's prior roles in family, career, and society that had given the person's life meaning; 5) not being able to spare loved ones from emotional, physical, and financial suffering; 6) causing others to suffer by their empathy for your suffering; and 7) the dread of leaving tarnished memories about yourself, with your future survivors. [3] Casually observing and then stating about a PLAD that "She's just sitting there" is significant complacency since its consequence is to not recognize PLADs' suffering as needing adequate treatment or if untreatable, to nevertheless prolong their lives.

The Natural Dying Living Will provides a way for your future physicians to answer the "when" question. This unique innovation relieves them of the need to assess your contemporaneous suffering. Instead, to determine if it is time to implement a previously chosen intervention, physicians need only ask:

> Have you, my patient, reached a condition that you previously judged would cause you severe-enough suffering to want to be allowed to die from your underlying disease?
> Or judged as causing exceedingly severe suffering so that you would prefer to lose consciousness that is also required to interact with others in distinctly human ways?

[1] Terman, S. A., Steinberg, K. E., Hinerman, N. (2024). Timely dying in dementia: Use patients' judgments and broaden the concept of suffering. *Alzheimer's Dementia*, e12527. https://doi.org/10.1002/dad2.12527

Step 2: Discuss your initial draft with an advance care planning counselor.

How it Works

You will receive a PDF of your **Initial Natural Dying Living Will** by email. It will have certain conditions highlighted that you can discuss with your ACP counselor by phone or by Zoom. Your responses should be consistent with each other, with generally accepted medical practice, and acceptable to your future physician. An example that does not fulfill these criteria is your asking for the intervention **Natural Dying** if you lost your ability to read a newspaper and balance a checkbook. If you made such an advance treatment decision, your counselor should inform you it is extremely unlikely your future treating physician would honor your request because it is **not** usual and customary to allow patients to die whose suffering is not severe. Your counselor could also point out that, with social support, you can likely enjoy other simple pleasures of life. Allowing you to die for these conditions could be deemed illegal and immoral. Note: These conditions are **not** among the 50 My Way Cards. Yet a well-known bioethicist/ attorney published his own living will in which he made this very request. [6] He was among the peers who wrote an open commentary that we debated in a journal of the Alzheimer's Association. [6]

Benefits

A review of your Initial Natural Dying Living Will considers: 1) Are your decisions consistent with each other? 2) Are they clinically appropriate—by insisting on severe, or exceedingly severe suffering? 3) Do they conform to generally acceptable medical practice? 4) Did you demonstrate diligence in making several changes that you explained? 5) Did you arrive at your final decisions deliberatively? 6) Have your decisions been consistent over time? Affirmative answers can help your agent persuade your future physicians and others to honor your wishes.

Why this Step is Unique

We know of no other ACP program that routinely offers ACP counselors' critical comments with the opportunity to discuss your initial responses, so you can diligently and deliberatively revise your living will. By the end of Step 2, you will likely have made all the changes you feel are important, so you feel at peace that your decisions reflect what you really want. (An optional-to-view video demonstrates this good result. [7]) Step 2 prepares you for your video-recorded interview with a clinician in Step 4.

Step 3: Form your Patient Decision Committee by including your agent and all alternate agents. Make advance decisions about more than treatment.

How it Works

You will receive your Final Natural Dying Living Will in two PDF formats. The shorter one ("By Condition") reflects your decisions in the same sequence as you completed the online program. It will also serve as the sequence for your recorded interview in Step 4. The longer one ("By Category") strives to be physician-friendly by using this clinical logic: it begins with the conditions you judged would cause exceedingly severe suffering, then severe suffering, next moderate suffering, and finally no or mild suffering. This format is designed to make it easy for your future treating physician to learn what intervention you would want for whatever current condition is most severe.

The "By Category" asks for more information and adds strategies so it can be effective. Examples are: Are there exceedingly severe suffering conditions for which treatment will be urgent? Which individuals do you want to serve as your agent and alternates, who will also be members of your Patient Decision Committee? Are there additional individuals you want to be non-voting advisors? Do you want to disqualify any individual from having any influence over your end-of-life decisions? Are there general types of health care institutions or specific ones nearly your residence, to which you do **not** want to be admitted (because they may not honor your end-of-life wishes)?

Your Final Natural Dying Living Will includes a strategy designed to motivate future physicians to honor your wishes. It warns them that they risk losing their legal immunity so they will become liable to being sued, if they do not honor your end-of-life wishes. Note that this living will provides only one layer of strategies; the next three steps provide additional layers.

Benefits

Members of your Patient Decision Committee will serve an important role: They will decide "when" to implement the interventions you want, although your future physician must still agree.

Why this Step is Unique

Many living wills require only a few checkmarks, initials, or a final signature to memorialize their treatment decisions. They do not ask for additional relevant information or add strategies. [5]

Step 4: Record your oral testimony on video as a trained clinician interviews you. Demonstrate your decision-making capacity. Add persuasive personal details and nuances for WHAT intervention you want WHEN, and WHY.

How it Works

Your interview with a trained advance care planning counselor/clinician can be recorded online using a HIPAA-secure version of Zoom (or in person if you prefer). The video can be stored on one or more of the following: DVD, USB drive, in the cloud on your server or on Caring Advocates' server. YouTube provides easy access if you are willing to accept its privacy settings. Most people consider accessibility more important than confidentiality for your completed Strategic Advance Care Plan.

Clinicians can conduct a semi-structured interview that also uses the collaborative, respectful approach described by the Emanuels in 1992. [8] Their "deliberative" physician-patient model strives to match your lifelong values to your selected treatment choices while applying gentle moral persuasion if needed to reach your goals. For each condition, clinicians will ask you four questions. Can you 1) Read the words; 2) Describe what is going on in the illustration; 3) Decide what intervention they want; and especially, 4) Explain why you made this decision? This approach can be referred to as "**RDDE**."

Benefits

Step 4 presents your own voice and face to inform others exactly what you have decided for each condition in your Final Natural Dying Living Will. Your presentation can help your loved ones feel at peace with your end-of-life decisions since you—not they—made these decisions, which you explained fully in your own voice. (It's best if your agent is present during your video interview.) The print version of any living will cannot provide relevant details and nuances along with your emotions, which may be needed to convince your future treating physician to honor your instructions. Your agent can show excerpts from your video to attain this goal.

If anyone questions if you really knew the consequences of your decisions, or whether you possessed decision-making capacity, they can view the relevant portions of your video. The last part of your video can have your clinician's opinion regarding your decision-making capacity. A qualified clinician is needed if you have a diagnosis that can affect thinking, memory, or judgment; for example, mild cognitive impairment, early-stage dementia, brain trauma, brain tumors, high doses of pain medications, and end-stage liver or kidney failure.

If your capacity is not likely to be questioned, and it would be a burden to pay the portion of a clinician’s fees not reimbursed by insurance, then your agent, a family member, or another person can conduct your video interview. Ask for our free guide to help this person conduct your interview.

Completing Step 4 may help 1) you avoid prolonged suffering; 2) reduce your loved ones’ anxiety about making the decision you want, which may in turn reduce their subsequent grief; 3) settle the issue about whether you had capacity to make informed decisions; and 4) provide your voice and face to help your agent convince your future treating physician to honor the wishes you expressed in your living will. Steps 1 to 4 can culminate in a comprehensive, compelling expression of what treatment you **want** in the print version, and video testimony of your living will. The next task is to add strategies designed to further motivate your future physicians to comply with your expressed wishes, and to deter others from sabotaging their orders so you **receive** what you want.

Why this Step is Unique

Checking boxes cannot fully reflect your nuanced wishes. Nor do they have the impact of persuasion based on the passion reflected by your face and voice. Recording your interview on video gives you an opportunity to fully express and memorialize your wishes about what you really want when, and why. The combination of **RDDE** and the “deliberative” approach to intervewing/consulting is in our experience, both unique and effective.

Step 5: Strategies so you receive the treatment you want, that prevent others from sabotaging your physician's orders and a bilateral contract with each agent to make certain wishes irrevocable.

How it Works

You will receive two PDFs: the Natural Dying Agreement (**NDAA**) and the Bilateral Durable Power of Attorney for Healthcare Decisions (**B-DPOAHCD** or **BPOA**) that includes specific, relevant legal/ logistical strategies designed to overcome common challenges to honoring your end-of-life wishes.

Prospective agents/Patient Decision Committee members who sign your bilateral agreement will thereby **promise** to: 1) serve as your steadfast, active advocate so others will honor the wishes you expressed your Natural Dying Living Will; 2) implement any relevant strategy if needed to attain your end-of-life goals; 3) insist your Natural Dying Living Will be followed even if you, as an incapacitated patient, have an "apparent" change of mind by expressing the desire to resume assisted feeding after you have reached a condition that you previously judged would cause severe-enough suffering to withdraw assistance with oral feeding; and 4) allow other members to observe their behavior of the currently active agent, so they can and vote on replacing this person if their efforts are either deemed **ineffective** (as defined in the Natural Dying Agreement), or if an alternate agent's background and experience will likely be more effective to convince your treating physician to implement a specific intervention.

Your advance care planning documents become legally valid if you swear/affirm an oath in front of a notary. Strategic Advance Care Planning uses **jurats** that ask you to state each document is "true, correct, and complete," so judges can admit the document into evidence in a lawsuit. Ironically, this strategy may lead to settling because your opponents may appreciate that your Natural Dying Living Will and Natural Dying Agreement may be considered "clear and convincing." If so, a judge may rule to honor your wishes and they will lose in court after wasting time, effort, and money. To save face, your opponents may cave and say something similar to, "The patient put in so much effort into expressing their wishes, this must be what they really want."

Benefits

Here are some examples of challenges in implementing the orders you need and potential sources of sabotage of these orders for which implementing relevant strategies is needed:

- You fear one or more of your relatives might try to influence your physician or a judge not to honor your end-of-life wishes based on their different (perhaps religious) beliefs.
- The dispatcher for first emergency medical responders transports you to a faith-based hospital whose clinicians or administrators refuse to honor your end-of-life wishes.
- The "you" whom you may someday become (your "future demented self") creates this "**classic conflict**" by expressing the **apparent** desire for assisted feeding to **continue**, but your past, capacitated planning principal wants assisted feeding to **cease** since you reached a condition that you judged would irreversibly cause severe suffering. (The term "classic conflict" reflects three decades of debate as bioethicists tried to agree on a resolution.)
- Third parties claim spoon feeding is not medical treatment, but basic care, which in some jurisdictions is not legal to discontinue. Others may claim that since you open your mouth and swallow what others put in, you changed your mind and revoked your living will. Some state laws do not permit incapacitated patients to refuse life-sustaining treatment—a legal challenge that must be overcome for you to experience a peaceful and timely dying.
- Your currently active agent does not advocate effectively for your end-of-life wishes but is not initially willing to step down to allow a designated alternate to better serve you.
- You need psychiatric medications to prevent you from hurting yourself or others, and to relieve your mental anguish but your physician cannot give you needed medication until a competent authorized person signs the necessary consent form. Delay can cause more suffering.
- You want to live where you are until you die. But after your facility administrators learn that your living will requests **Natural Dying** or **Moderate Anesthesia**, or that you may decide to Voluntarily Stop Eating and Drinking (**VSED**), they inform you that their risk-management attorneys advised them not to honor your requests.
- After you have lost capacity, your future physician selects a legally recognized decision-maker (**surrogate**) to consent to the orders in your **POLST**. But this person either does not know what you want, believes another treatment decision would be in "your best interest," or was chosen to serve as your future physician's rubber stamp. You want instead a person who knows your values and will advocate for your original requests. No person is more qualified to fill this role than you. This is why you have insisted on completing your own **POLSTs**.
- You want total relief from all types of unbearable pain and suffering. But your physician fears others will criticize them for committing "slow euthanasia," or for not following the American Medical Association's ethical guideline that states, "Palliative Sedation is not an appropriate response to suffering that is primarily existential." But you want relief from all types of severe suffering and to receive adequate sedation/anesthesia if less-sedating treatments have failed.

- Many states mandate certain professions to report the suspicion of elder or dependent person abuse. Anyone can submit an anonymous request for an investigation. Some misguided third parties may believe that withdrawing assisted feeding is neglect or abuse. For example, they may incorrectly allege, “She had been opening her mouth and swallowing, but now they are starving her to death.” You want a timely dying that takes two weeks—not two years—and to avoid the hunger that can accompany slow starvation. Some advanced dementia patients lose 40% of their weight before they die, but sadly have lost their ability to complain they are suffering. You do **not** want your end-of-life goals derailed by a report of suspicion that provokes a long investigation that, regardless of the ultimate outcome, prolongs your dying and suffering. You especially do not want a judge to issue a TRO (Temporary Restraining Order) that prevents your loved ones from moving you to a private place (such as your own home) to attain your end-of-life goals.
- The legal department of the facility where you reside points out that the statute in your state, or the regulations of Medicare, or the policies of another oversight organization, require them to always **offer** you food and fluid—but they choose to interpret “**offer**” as meaning to put food and fluid in your mouth, rather than to place them within your reach.
- You reside in a nursing home or memory care unit whose medical director is a member of AMDA-The Society for Post-Acute and Long-Term Care Medicine or who agrees with their now-retired Policy A19. From 2019 to 2023, this policy “recommend[ed] adopting a policy of comfort feeding for all nursing and assisted living facility residents with advanced dementia, despite any advance directives to the contrary. The Society affirms the right of **all** … residents to receive comfort feeding until their behavior indicates **refusal** or **distress**.” [9] (Note that **refusal** and **distress** are opinions of these physicians.)
- Policy A19 recommended practicing **paternalism**, based on these criteria: 1) your physicians acted as if they knew what is in your “best interest” **better** than you could have known—even though you completed advance care planning with adequate counseling when you had capacity; 2) they made this treatment decision for you unilaterally without your knowledge or your consent (since you cannot give consent if you lack decision-making capacity); and 3) they were fully aware that both you and your agent expressed the opposite instructions.

Summary: Intense opposition to **Natural Dying** and **Moderate Anesthesia** can come from various disciplines. Additional strategies and effort may be needed to succeed where, by itself, living will fails:

That is what this slogan means:

Plan Now to Die Later®—to Live Longer.

Step 6: Complete a series of "Future POLSTs" and record a short instructional video for each. Store your videos and documents until it is time to inform all concerned which "Future POLST" is currently implemented.

How it Works

Your forms and videos must inform emergency medical personnel first responders and physicians exactly what treatment you want—so they can write and implement orders that fulfill your wishes. The main role of your Patient Decision Committee is to decide **when** you would want your present **POLST replaced by another POLST**. Their decisions will be based on your significant change in clinical condition. You can record a short instructional video for each **POLST**, to clarify **what** you want; for example, your face and voice can demand: "Do not start an IV. I want no fluid by any route. I am on a total fast of all food and fluid. My goal is to experience a peaceful and timely dying. Even small amounts of fluid will prolong my dying."

During advance care planning, you can meet with a healthcare provider and have a "POLST Conversation," that you can memorialize on video. Since you will have capacity, you can receive adequate information about the set of orders in each **POLST**, and voluntarily give your **informed consent** to each Future POLST that will be implemented only if you reach a specific future clinical condition that your Natural Dying Living Will described. Example: if you reach a condition that you judged would cause severe suffering, the implemented **POLST** will include orders for **Natural Dying**. Since **Future POLSTs** are part of your advance care planning, you can sign them in front a notary.

POLSTs are the most powerful documents to determine your end-of-life treatment for three reasons: (A) they possess the power of physician orders; (B) they are immediately actionable; and (C) other healthcare providers must follow these orders (unless they claim a moral conflict or allege your request is contrary to accepted medical practice in most states). The **National POLST** form is recommended in addition to your state's form since it avoids certain inconsistencies in the statutes of some states (including California). Also, if you visit another state, its physicians may be more willing to practice reciprocity if you have a **National POLST**. (Note: There is no research on the last point yet.)

This final step offers you several ways to inform others **what** you want, the option to choose **where** you want to receive effective comfort care and end-of-life care, and advanced security technology that can detect whether any document was **modified** after you signed it.

Benefits

Using **Future POLSTs** gives you the opportunity to make decisions yourself and makes it difficult for future treating physicians to impose additional criteria to honor your living will (by practicing paternalism) so you can attain your goal of a peaceful and timely dying. Here are some details:

Strategic Advance Care Planning departs from the traditional practice that waits until you have become frail, seriously ill, or terminally ill to complete the **POLST** that you then need. Instead, it recommends you complete all **POLSTs** during advance care planning. Waiting is not advised since you will have likely lost capacity to consent to a **POLST**, in which case your treating physician must ask your agent to consent. But research reveals that agents cannot accurately guess what patients want. Shalowitz et al. (2006) found only 68% agent-patient concordance for making decisions for all diseases. The result for patients was 58% for patients who had strokes or dementia (barely better than flipping a coin. [10] You cannot trust your agent to make the same treatment decision you would make. Agents may also encounter formidable challenges and obstacles when they try to persuade your future physician to implement the orders you need. Elsewhere, I use these reasons to argue that providers have a **moral imperative to inform** planning principals of this reality during advance care planning.[11]

If **you** complete your own **Future POLSTs**, your future physician cannot select a rubber-stamping “legally recognized decision-maker”—especially if each **POLST** includes two orders: “**POLST** orders must be consistent with patient’s advance directive” and “No one but the patient can sign a **POLST**.”

Challenges can occur after implementing the **Natural Dying POLST**, such as the **classic conflict**. As described above, your living will directs cessation of assisted feeding but your “future demented self” apparently indicates the desire for assisted feeding to **continue**. To prevent this conflict from emerging, during advance care planning each agent and you can sign a bilateral, irrevocable contract that empowers your currently acting agent to override desires expressed by your “future demented self” if not consistent with your Natural Dying Living Will. This strategy may prevent physicians from justifying their practice of paternalism as in AMDA’s ethicists’ Policy A19:

> **We (providers)** either violate the entire concept of advance directives and practice an injustice against the person as they once were, or **we** refuse to feed our patient and

> practice an injustice against who they are now. The **provider must** recognize this and then **choose** the injustice that does the least harm. [9]

Comments: The ethicists' justification is arrogant, wrong, and illegal but the policy was in force for four years and a survey showed about half of individual providers still continue to follow it. [12] The law states that providers cannot make treatment decisions for you. Furthermore, AMDA's ethicists likely committed the fallacy of bifurcation by arguing that only two choices are available. This helped them make this argument: If one choice is wrong, then the other—which they prefer—must be right. But there are more than two options. A third is your signing the recommended bilateral contract and thereby empowering your proxy/agent. Also, since **POLSTs** are immediately actionable, others will have no time to impose clinical requirements in addition to your Natural Dying Living Will before honoring your instructions. These reasons for signing a bilateral contract strategy may reduce your worry that others will force you to endure unwanted prolonged dying and suffering.

Where do you want to receive Comfort Care?

If you want Full Treatment, you can accept a **POLST** that sends you to a hospital, if needed. But for all other levels of care, this conditional **POLST** order that appears on many **POLST** forms may be exactly what you do **not want**: "Transfer to hospital *only* if comfort cannot be achieved in current setting." You may prefer to return to your home, a residential hospice, a hotel, or wherever the members of your Patient Decision Committee agree is best, when this decision must be made. If you may want to Voluntarily Stop Eating and Drinking, to be allowed to die by **Natural Dying**, or to receive **Moderate Anesthesia** for exceedingly severe suffering then you do **not want** to be transferred to any healthcare facility whose authorities have power to thwart your end-of-life wishes.

Why this Step is Unique

Completing **Future POLSTs** differs from the traditional protocol in several ways:

- **POLST** conversations are held during your advance care planning—not just before their orders are implemented when you become seriously ill—and you record video instructions, which a research study indicated improves accuracy of emergency medical personnel responses. [13]
- Two additional orders can exclude others from signing a new **POLST** and can ensure your **POLST** is consistent with your Natural Dying Living Will.
- Your **POLST** can express your choice to be transferred to somewhere other than a hospital.

- Your agent is more likely to succeed in persuading your future physician to **implement** your **POLST** if this **POLST** already exists (which your previous healthcare provider adequately informed you about, and you signed to consent). Since your future treating physician can follow medicine's usual and customary practice—to honor the previous physicians' orders (unless there is a good reason not to do so)—this innovation helps make your plan effective.
- You can choose from a range of ways to inform concerned others how they can access your forms and videos, and importantly learn which **Future POLSTs** is currently implemented.

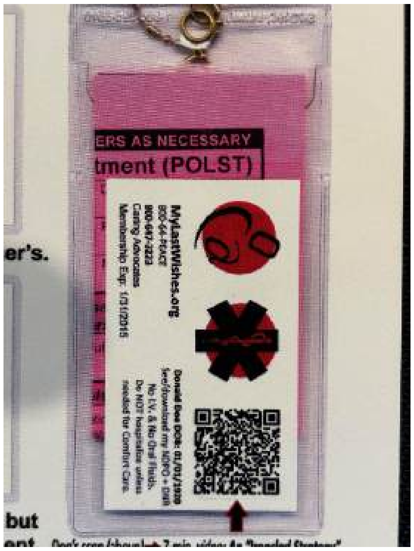
Advanced security technology is an easy innovation to choose

Traditionally, providers and patients signed in person with **"wet" signatures** and used local notaries for convenience. But you may want to use the advanced security features of **digital signatures** that only **Remote Online Notaries** (**RONs**) can offer. (Electronic signatures only verify signers' identities.) **Digital signatures** require an algorithm that uses personal and public keys contained on a specific device, to assure that your document was **not tampered with or modified since you signed it**. A video recording of your signing visit further decreases potential conflict. Additional security is warranted since the orders for **Natural Dying** and **Moderate Anesthesia** are controversial. In addition to preventing fraud, adding security is a testament to your intense motivation to control what treatment you want to receive, and when, as your life ends. Why is following this recommendation "easy"? Compared to in-person notarization, the cost of notarization is about the same, but the time required to complete the process is much less.

Step 7: How to store and provide access to your documents and videos.

To inform all concerned which **POLST** is currently implemented, and to provide access to all your forms and videos, you have several choices that can change, depending on which **POLST** is currently implemented. For example, if you are physically active, you can wear a DNR bracelet or pendant (if your state allows), but if you are seriously ill, you can wear your folded **ND-POLST** or **MA-POLST** in a large plastic badge attached to a lanyard, so that it lies on your chest. You can also display a barcode that links to each of your documents and videos. You can also store all forms and videos in a registry, such as **MyLastWishes.org** that allows your documents and videos to be downloaded and/or viewed. Other registries can work if its administrator agrees to release the appropriate forms only when your currently acting agent authorizes them to do so.

Below are two examples of how you can display your **POLST** and use a barcode to access all your documents and videos: On the left is a small plastic badge that you can wear or you can just keep the business-size card in your wallet or purse; On the right is a large plastic badge with your currently active folded **POLST** that you can wear if you become seriously ill.



Summary and encouragement

Many people feel overwhelmed after their initial reading of this overview. But keep these points in mind: First, this document presents you with the entire process; but after you embark on this journey, you will learn or be reminded of details on a as you "need-to-know" basis. Second, a health care provider or advance care planning counselor will provide guidance for each step of the way. Finally, you can determine the pace with which you are comfortable. The range is from a couple of weeks to a few months. In my experience, very few motivated patients stopped this process after they began.

> *Note: This overview and the documents to which it refers are in continual improvement. All are subject to change. Upgrades are available for those who completed advance care planning prior to 2024 and can be tailored to focuse on just what they need.*

For More Information:

Website: www.caringadvocates.org

Learn from Media: "Living with Advanced Dementia--What is it really like? Feb 4, 2017."

This is a 14-minute glimpse of why many lay and professional people consider Advanced Dementia to be the cruelest, most burdensome, and most prolonged of any terminal illness for patients, loved ones, and caregivers: https://youtu.be/jnZOLOliDwQ.

Might a relative or someone you know need NOW Care Planning, our companion program?

If you are concerned about a relative who has already reached a stage of advanced dementia but who has an ineffective living will—or none at all—you can learn about our other protocol, Now Care Planning, at: https://caringadvocates.org/ncp.php; and begin your efforts at: www.tinyurl.com/NowCarePlanning.

Citations

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2. Visit www.CaringAdvocates.org for more information.

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NOW Care Planning—a Caring Advocates Protocol

NOW Care Planning is a legal, ethical, moral protocol to respectfully decide and effectively implement a **treatment of last resort**—a medical intervention considered only after less drastic options failed to relieve a patient's severe, irreversible (refractory, untreatable) end-of-life suffering. The protocol strives to be consistent with the patient's lifelong values and treatment preferences; that is, to provide "goal-concordant care." Often, strategies are needed to overcome challenges to implement these interventions because they are controversial. A possible, foreseen, but unintended outcome is attaining a peaceful, timely dying—but its primary goal is to relieve suffering, **not** to hasten death.

NOW Care Planning is designed for patients who have already reached an advanced stage of dementia or other terminal illness that has rendered them unable to speak for themselves: they lack decision-making capacity (**DMC**) *and* they did **not** previously complete an **effective** living will to attain their goals for their current condition.

The protocol serves two types of patients. Neither depends on high-tech medical treatment that can be withdrawn or withhold to allow them to die naturally. They have "No plug to pull."

(A) Those with **severe** refractory suffering who depend on another person's hand to put food and fluid in their mouth to survive—a treatment that is legal to refuse.

(B) Those with **exceedingly severe** refractory suffering for whom all reasonable non-sedating methods of treatment have failed (or would likely fail) to provide relief, who can still eat and drink independently (without another's hand assistance).

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(C) Note: NCP is **not** needed for patients at risk for contracting aspiration pneumonia—a way to die that can be unpleasant—for which it is legal to withhold food and fluid.

Benefit: NOW Care Planning can make it possible to avoid prolonged suffering for several months or years that includes suffering from sources that **cannot be observed** or **be treated**.

Two treatments of last resort:

Natural Dying (ND): This intervention refuses assisted oral feeding and hydrating by another person's hand while always offering food and fluid by placing them within the patient's reach. Unless the patient resumes eating and drinking, which is possible but would be surprising, dying by medical dehydration usually occurs within two weeks of beginning a total fast of food and fluid. The process of dying is most often peaceful with minimal medication. Spoon-feeding, like any other invasive treatment that violates a patient's bodily integrity, can be viewed as legal, ethical, and moral to refuse.

Moderate Anesthesia (MA): Using medications to sedate patients to either relieve the offending symptoms (for example, psychiatric symptoms), or to make patients unaware of these symptoms due to deliberately diminishing their consciousness.

Consent: The legally designated, currently active proxy/agent must sign a consent form on behalf of the patient that acknowledges being adequately informed by the physician/provider about two foreseen but unintended possible side effects:

(A) The patient might die earlier with either ND or MA as the treatment of last resort.

(B) The patient may not regain consciousness before dying with Moderate Anesthesia.

To be effective, living wills must be **acceptable** to authorities who have the power to agree to implement orders and let those orders stand. Otherwise, any requested intervention would be effective only in theory—not in practice. **Effective** means a physician or provider promptly (without conflict) writes and implements a clinically appropriate **POLST** that contains the medical orders the patient needs.

Reasons why POLSTs are well-suited for NOW Care Planning: (**POLSTs** were formerly called Physician Orders for Life-Sustaining Treatment although their names varied among American states):

(A) POLSTs have the authority and power of physician/provider orders (that exceeds an instruction in a living will or from a proxy/agent)

(B) POLSTs are immediately actionable, so there is little time for conflicts to emerge

(C) Orders apply in all treatment settings including home, long-term residences such as memory units, assisted living facilities, and skilled nursing homes, and hospitals.

The ethical process: Treating physicians/providers must diligently discuss POLSTs with the legally recognized proxy/agent regarding whether the POLST is clinically appropriate. They must also adequately inform them of the implementation's benefits and risks. To implement the POLST, both must sign the POLST form—an act that indicates the proxy/agent consented on behalf of the patient after the physician/provider shared adequate relevant information.

How the treatment decision is made:

Substituted Judgment (SJ) is a widely accepted bioethical practice of making treatment decisions for a person who lacks DMC. The goal is to make the same treatment decisions for the current condition that patients would have made for themselves if they had DMC.

NOW Care Planning expands the traditional process in two ways: by the number of people asked for their SJ opinion, and by the number of conditions they are asked to judge regarding how much suffering they would cause.

Traditionally, one individual (the currently acting proxy/agent) is asked just one question about treatment for just one clinical condition (the patient's current condition).

> "In your opinion, what specific treatment would the patient want **now**—given his/her present clinical condition(s)—if s/he had been asked a few years ago, when s/he possessed decision-making capacity (DMC)?" (This is the classic **SJ** question.)
>
> An alternative **SJ** question is: "In your opinion, what specific treatment would the patient want **now**—given his/her present clinical condition(s)—if somehow (magically) the capacitated version of the patient could return long enough to observe the current state of the patient and to make a deliberative decision now?"

The **NOW Care Planning** Protocol expands the effort to gather a robust set of data upon which life-determining decisions can then be made. These are the **6 steps**:

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1. The currently acting proxy/agent forms a new Patient Decision Committee **(PDC)** by inviting all alternate designated proxies/agents. The PDC can also include individuals who know the patient well such as other family members and those whose specialized background may be helpful. They can offer their advice, but they are not asked to vote based on their substituted judgment.

2. When anyone believes the patient's suffering has become severe, all available PDC members should schedule a meeting to discuss if other interventions possibly need to be implemented now.

3. To help PDC members decide, they can complete one or both of Caring Advocates' free forms. One is: "**Are you concerned about someone who is dying slowly from dementia, and might be suffering?**" This is available at: https://www.surveymonkey.com/r/Now-Care-Planning-for-Dementia

   Another form is: **"Now Care Planning: Does your loved one resist spoon-feeding?"** This is available at: https://www.surveymonkey.com/r/Relative-resist-spoon-feeding.

4. Each PDC member then uses the patient decision aid, **My Way Cards**, to render their opinion based on their substituted judgment and their knowledge about the patient's lifelong values and treatment preferences to judge the severity of each of 49 conditions.

   There are four levels of severity, four possible interventions, and four corresponding POLSTs. They start with Selective/Limited Treatment—first with, and then without CPR (DNR).

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Natural Dying and Moderate Anesthesia are two treatments of last resort.

Example: If there are 5 currently acting proxy/agent, including four designated alternates who complete the patient decision aid **My Way Cards**, then there will be 5 X 49 or 245 pieces of data. Presenting the results—if there is agreement—may help persuade a future physician/provider to implement the appropriate POLST.

5. An ACP counselor will review all questionnaires and My Way Cards data and hold a conference with the available PDC members. They can discuss the results, debate differences, change their minds, and possibly reach a "consensus of substituted judgment." If they cannot agree, they must wait until the patient's clinical condition changes further.

   If PDC members agree that one or more conditions are **now** causing severe suffering, then they can authorize the currently acting proxy/agent to advocate for implementing the **Natural Dying POLST** in a shared decision-making/POLST Conversation with the treating physician/provider.

   If PDC members agree or that two or more conditions are **now** causing exceedingly severe suffering and the patient can still eat and drink without assistance, they can then authorize the currently acting proxy/agent to advocate to implement the **Moderate Anesthesia POLST** in a shared decision-making/POLST Conversation with the treating physician/provider.

6. The ACP counselor can provide the currently acting proxy/agent a blank POLST form to which the needed orders for the treatment of last resort have already been added (for the convenience of the

treating physician/provider).

The ACP counselor can also print a cover letter summarizing the consensus of substituted judgment data that appears in a Table in this letter, and a boilerplate letter that the physician/provider can optionally modify, sign, and send to a bioethicist or independent clinician to request a second opinion regarding the appropriateness of implementing the requested treatment of last resort.

When the currently treating physician/provider is comfortable with implementing the treatment of last resort, the signed completed POLST can be implemented.

Safeguards and Strategies:

(A) The robust set of data collected can be combined with convincing arguments to persuade treating physicians/providers to comply with patients' wishes. These arguments can be in several fields, including medicine, geriatrics, dementia, end-of-life suffering, bioethics, law, philosophy, and religion.

(B) A counseling healthcare provider can guide the legally designated currently active proxy/agent and alternates, and concerned others, through the protocol. It is essential that the goal of substituted judgment is understood: It strives to arrive at the same set of treatment decisions for the current condition that patients would have made themselves, if they had capacity. It is **not** what the surrogate would do for himself or herself, or what the surrogate thinks is best for the patient. It is what the patient would have decided (worth repeating).

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(C) If the currently treating physician/provider delays or refuses, the currently acting proxy/agent can seek another provider and/or follow one of several strategies from Strategic Advance Care Planning that may be applicable.

(D) One advantage of the NOW Care Planning Protocol is to spread the responsibility among several people for making a life-determining treatment decision for another human being. This is in addition to emotional support, that is likely enhanced by having a group meeting with the ACP counselor. It is also likely that the decision arrived at, and when to implement it, are more accurate than if only one surrogate had been asked. Finally, the treating physician/provider may be impressed by the number of surrogates who agree with one another and that they asserted they know no one who may have legal standing who would oppose implementing a treatment of last resort.

(E) In NOW Care Planning, every patient and their proxies/agents are different; hence the approach needs to be personalized. That makes the above a general guide regarding what to expect.