

## 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, 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 past shared experiences.

The number of persons now living in advanced dementia (PLADs) is likely over two million in the U.S., 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 (**SACP**) 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.<sup>[1]</sup> 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.<sup>[2]</sup> 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<sup>[3]</sup>; that is, stop putting food and fluid in the patient's mouth. Terman's article explained why this treatment is arguably moral.<sup>[4]</sup> 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.<sup>[2]</sup> 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:

- **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,<sup>1</sup> which begins below.
- **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 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]

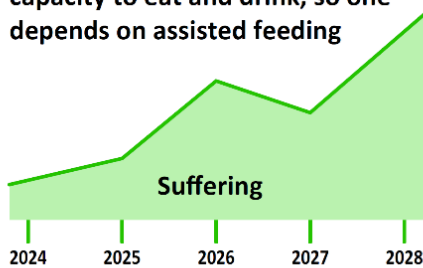
Many patients have a great but relatively unappreciated challenge: They live in the **Dementia Gap**. While their suffering is exceedingly severe suffering, they can still eat and drink independently, so they **cannot** rely on an advance decision to refuse **assisted** oral feeding and hydrating (**Natural 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?

<sup>1</sup> 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 deliberately? 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 deliberately 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 nearby 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 interviewing/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<sup>®</sup>—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**

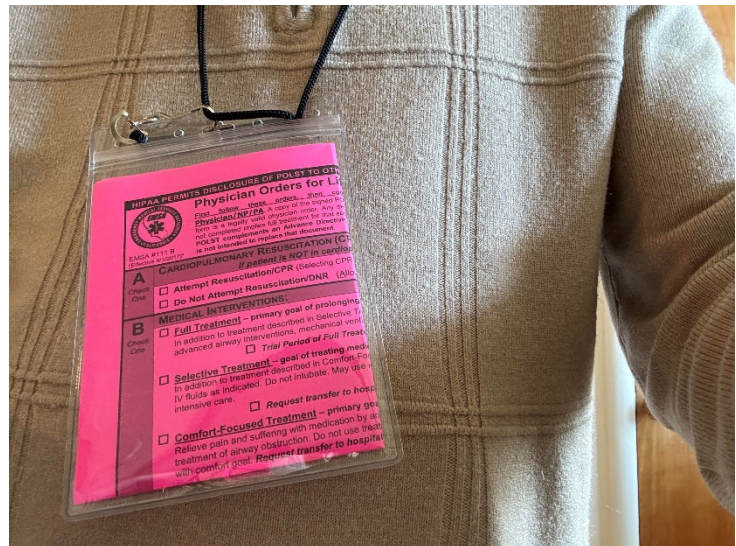
Traditionally, providers and patients signed in person with “**wet**” **signatures** and used local notaries for convenience. But you may want to use the advanced security features of **digital signatures** that only **Remote Online Notaries (RONs)** can offer. (Electronic signatures only verify signers’ 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 “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 limited to just what they need.*

## For More Information:

**Website:** [www.caringadvocates.org](http://www.caringadvocates.org)

**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>.

**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](http://www.tinyurl.com/NowCarePlanning).

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