Six Steps to Strategic Advance Care Planning

➔ The goal of **Strategic Advance Care Planning** is a **private**, **peaceful**, and **timely dying** so you can feel peaceful about your plan *now*. Confidence that your plan will succeed—meaning that others **will** honor your wishes when you cannot speak for yourself—can prevent you from considering hastening your dying as the "only certain way" to prevent being forced to endure an unwanted prolonged dying with suffering.

➔ **Steps 1 to 4** let you clearly state **what** treatment you want **when** (condition). **Step 5** includes **strategies** designed to motivate your future physician to write the orders you will need, and to prevent *anyone* from sabotaging your goal. **Step 6** is an optional way to make all your forms and videos available to clinicians when needed.

We recommend completing all steps, but you can complete as few as one, if you wish.

Step 1: Complete your "INITIAL Natural Dying Living Will."

How it works:

Step 1 uses the online *patient decision aid,* **My Way Cards**. Each card describes one of about 50 conditions by words that are easy to understand and a line drawing. Together, these conditions strive to comprehensively reflect what people dread most about being forced to endure a prolonged dying in advanced dementia and other terminal illnesses. Describing conditions behaviorally makes diagnosis is less important than loss of function or unwanted behaviors. Example: A person can completely lose the ability to respond to others due to advanced dementia, total paralysis due to ALS, strokes, or severe brain trauma. Most planning principals care more about losing function and severe suffering than their specific diagnosis. (People who want to live as long as possible—regardless of suffering—can also use this *patient decision aid*.)

Use your computer, tablet, or cellphone to complete Step 1. Note: Real, printed (non-virtual) cards that can be spread out on a table are available but infrequently used today.

Make an "advance treatment decision" one condition at a time, by answering **one question**:

> "In your judgment, will this condition—by itself—cause **severe enough suffering** for you to want **Natural Dying**?"

If your answer is, "No, not enough suffering," then others will continue the default option, **Feed and Treat** and your physician will order treatment to try to keep you alive as long as possible.

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If your answer is "Yes, suffering from this condition would be severe enough," then future physicians and others can *allow you to die of your underlying disease* by implementing **Natural Dying** (defined below). **Natural Dying** can be clinically **effective**—even if you have "**No Plug to Pull**"; that is, if sustaining your life does **not** depend on receiving any high-tech medical treatment since the only treatment you need is spoon-feeding.

The criterion of **severe suffering** is more **compelling** than the criteria traditional living wills use to answer the "**When Question**." Some examples are: reaching a sub-stage of disease is arbitrary; inferring if your feeding behavior is resistant is prone to misinterpretation; applying the "Principle of Proportionality" is laudable, but vague; and judging your "Quality of Life" is very low or you now live in a state of "Indignity" could begin a dangerous slippery slope that could lead to granting some people authority to judge if the lives of others are *worth living*.

Natural Dying also strives to be widely **acceptable** by resisting the intent to hasten dying. The intervention *withdraws assistance* by another's hand with hand-feeding and hand-hydrating, but it *never withholds food and fluid*. Instead, it includes this physician order, "*Always* place food and fluid in front of the patient and within his or her reach." Fact: Natural Dying can be **effective** in practice only if those in authority **accept** it. Thus, it strives to be clinically appropriate, legal, ethical, moral, and consistent with the teachings of major religions.

For those who do not continue other Steps at this time, this can be their "CURRENT" living will.

BENEFIT:

➔ **Educates** you what it can be like, for you and your loved ones, to live with advanced dementia and other terminal illnesses—both by the cards and the optional online videos.
➔ **Facilitates** your making a clear and specific advance treatment decision for each condition. Lets you express "what" intervention you want "when," where timing is based on **your values**.
➔ **Memorializes** your requests so future physician(s) and others will know what you want.
➔ **Reduces** your proxies/agents' emotional burden by making their primary role to serve as your advocate so others honor the treatment decisions that **you** previously made **yourself**. (Traditional advance directives primarily empower proxies/agents to make current treatment decisions on behalf of the incapacitated patient using their "Substituted Judgment.")

Why this step is unique:

➔ To our knowledge, the Natural Dying Living Will asks for your judgments about more conditions (50) than any other living will (typically, less than 6).

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➔ No other living will insists on "**severe enough suffering**" as the sole criterion for "When?" and broadens the concept of suffering to include: physical pain and suffering; emotional or psychic suffering; existential suffering (loss of meaning in life, fear of dying); disruption of one's life narrative; and not being able to spare loved ones various types of suffering. Together, these areas of suffering are what people dread most about prolonged dying in advanced dementia.

➔ No other living will offers a way for physicians to answer the "When Question" so they do **not** need to assess your current suffering. To determine if "that time" has come, physicians only need to answer this key question: "Have you, my patient, met the clinical criteria of at least one **condition** that you **previously judged** would cause **severe enough suffering**?"

Step 2: Discuss your "Initial Draft" with a healthcare provider counselor.

How it works:

You receive by email, a PDF of your "INITIAL Natural Dying Living Will" along with our written comments. You and one of our staff then discuss your decisions by phone. (Your discussion may be part of an advance care planning counseling session covered by insurance.)

BENEFIT:

The review of your "INITIAL Natural Dying Living Will" asks if your decisions are **consistent** with each other; **credible** by insisting on severe enough suffering; clinically appropriate; and conform to generally acceptable medical practice. If you can demonstrate you arrived at your decisions after **diligent, deliberative discussion**, your proxy/agent may find it easier to motivate your future treating physician to write orders to honor your end-of-life wishes. Revisiting your decisions a few times helps demonstrate your decisions were **consistent over time**. This modest amount of additional effort now may prevent long conflicts in the future.

Why this step is unique:

To our knowledge, no other organization provides comments and discusses "INITIAL" responses with planning principals. We have over eight years of experience in helping patients consider the best advance treatment decisions for their future incapacitated selves. Typically, people change 1 or 2 decisions, and few change more than 10.[1] Yet planning principals often feel these changes were important so they then feel at peace with a completed living will that reflects what they *really* want. Completing this step is thus highly recommended over a possible

[1] For example, view the video from Melissa Cook's Step 4: **Why I Changed My Mind--From Natural Dying to Treat & Feed--for Certain Symptoms of Advanced Dementia** (20 min. 8/2012). youtu.be/qA0TQS1Pmwk

alternative: To consider your INITIAL living will as your "CURRENT Natural Dying Living Will." Yet some people choose to stop after the complete Step 1, also known as "The Good Initial Plan," and they can resume advance care planning by completing other steps later on in their lives.

Step 3: Again, use the online patient decision aid, My Way Cards. This time you will complete your "FINAL Natural Dying Living Will."

How it works:

Consider your discussion in Step 2 and any thinking, reading, viewing of instructional videos, and discussions with family members, proxies/agents, and trusted authorities and counselors. After you complete the online program again, we will send you a PDF by email. You can review it and make any needed changes. Then we will send you by U S Postal Service, an addition format of your "FINAL Natural Dying Living Will." Both are printed on heavy stock, color paper. One format is convenient to compare your responses at different times. The additional one is "user-friendly" for physicians to learn what you want, and when. You also receive these forms to add to your living will:

(A) **Consent for Palliative Sedation to Relieve Unbearable Suffering**;
(B) **Do not force-feed me**; and,
(C) **Don't give me thickened food and fluid**.

You can sign these forms and have them witnessed or notarized to make them legally valid.

Important: You can always change your decisions as long as you still have mental capacity by completing an "Updated Final" Natural Dying Living Will. Once you lose capacity, your living will serves as the durable expression of your end-of-life wishes.

BENEFIT:

This step lets you show you made these difficult, possibly life-determining decisions after diligent, deliberative discussions and that most decisions were consistent over time.

Your "FINAL Natural Dying Living Will" includes a strategy to motivate future physicians to honor your wishes. It warns all healthcare providers that they risk losing their legal immunity, which opens them to being sued—if they ignore your known, end-of-life wishes.

Why this step is unique:

We are not aware of any other organization that offers planning principals **two opportunities** to make advance treatment decisions as they complete their living wills. Most require only one or a few checks or initials, to indicate a selection of one from several choices. Some living wills

ask only for a signature at the end of the document. We are not aware of other living wills that "warn" physicians about possible lawsuits if they ignore your known end-of-life wishes.

Step 4: RECORD your oral testimony on VIDEO during an interview. Use this opportunity to explain WHY you made each treatment decision, and to add personal DETAILS. Demonstrate your decision-making capacity.

How it works:

Your interview can be in-person in our office, or where you currently reside. If you find it hard to travel or if you live far from our network of counselors, you can use our HIPAA-compliant Internet video program. We can send the interview video to you on a thumb drive and/or upload it to YouTube using its privacy settings and/or store our own server.

BENEFIT:

Step 4 lets you inform others exactly what you want for each treatment decision in your "Final" Natural Dying Living Will. This is your opportunity to **convince** your future physician(s) and others to honor your requests. Finally, those who view the video can assess if you had **capacity** (were mentally competent) to make these decisions. Capacity requires these abilities: (a) to **understand** and (b) to **appreciate** the consequences of the two treatment options, which are Treat & Feed *versus* Natural Dying; (c) to use logical **reasoning** to reach a set of treatment decisions; and (d) to **express** those decisions **consistently** over time.

Step 4 is especially important for patients who have a diagnosis or condition that may affect their thinking, memory, or judgment. Examples include: Mild Cognitive Impairment; Early Dementia; brain trauma or tumors; high doses of medications to relieve pain; and liver or kidney failure. Your interviewing counselor can express and record on video, his or her clinical opinion about your capacity. This can carry more clinical and legal weight than a lay person's opinion regarding your "sound mind," which is all that traditional living wills typically require of witnesses. Trained counselors can follow a semi-structure interview to elicit your responses. In the future, other clinicians can view the video to assess your decision-making capacity. The goal is to prevent future conflict so that others will promptly honor your end-of-life wishes.

Note: Checking a few boxes cannot fully reflect your nuanced wishes and strong feelings. After you complete you video, you may feel at peace because you will have fully expressed your wishes. Then, if someday you lose capacity and cannot speak for yourself, others can view your video to learn what you *really* wanted, and why, and confirm you had capacity.

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Completing Step 4 can: (A) help you avoid prolonged suffering; (B) reduce your loved ones' anxiety about making the decision you want (that may in turn, reduce their grief); (C) settle the issue that you had having capacity to make informed decisions; and, (D) help your proxy/agent persuade your treating physician to write orders to honor your end-of-life goals.

Why this is unique:

To our knowledge, no other organization uses a semi-structured interview that follows guidelines developed over several years of professional experience whose goal is for counselors to elicit your end-of-life wishes as fully as possible. Nor do other organizations structure the interview so a counselor intentionally prompts responses that can allow him or her to form and express an opinion regarding your decision-making capacity.

Completing Steps 2 through 4 constitutes the "Better Diligent Plan." If you want someone other than a Caring Advocates-trained clinician to conduct your video-recorded interview, we can provide a set of recommended guidelines that your choice of interviewer to follow.

Step 5: Strategies to motivate your physician to write the orders you need, and other strategies to prevent anyone from sabotaging your plan.

How it works:

We send you a PDF that includes a set of specific, relevant legal/medical/logistical strategies, called the **Natural Dying Agreement** and the **Natural Dying Affidavit**. These documents are given to each individual who is willing to become a member of your **Decision Committee**. Each individual must sign a page that makes the durable power of attorney for healthcare decisions a "bilateral contract." In signing each agrees to: (A) Serve as your advocate so others will honor your end-of-life wishes. (B) Implement any strategy needed to fulfill your end-of-life goals. (C) Let others observe their behavior if they are your currently active proxy/agent and agree to being replaced by another member of your "Decision Committee" if others judge their behavior as *ineffective*, which the Natural Dying Agreement defines and exemplifies.

The Natural Dying Affidavit lets you swear in front of a notary that your declaration is "true and correct." This makes it possible for a judge to admit the Natural Dying Affidavit into evidence. Ironically, this strategy may prevent going to court. Here's why: If opponents read your Affidavit and fear a judge will rule to honor your wishes, then they will likely not want to go to court where they will lose after much effort and expense. Instead of admitting that, they could say, "We see how much effort the patient put into expressing her wishes, which she must really want."

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Note: These strategies have been reviewed by clinicians and attorneys and they *seem effective* on their face, but few have been tested in court. There is a good reason: the goal of Strategic Advance Care Planning is to have a private dying. To fulfill this goal, conflicts at best do not arise, or at least are resolved at the bedside, but do **not** escalate to court. Unfortunately, the media mostly reports conflicts to sell copy, and rarely report cases that are quietly successful.

BENEFIT:

You can put into place a comprehensive set of strategies designed to persuade your physician and others to honor your end-of-life wishes and to overcome common challenges who might otherwise sabotage your goal of attaining a **private**, **peaceful**, and **timely dying**.

➔ Fourteen examples of challenges and potential sabotage that can occur after you reach a condition that you previously judged would cause **severe enough suffering** to want others to implement Natural Dying, which includes the physician order **to stop hand-feeding and hand-hydrating (spoon-feeding)**:

(A) You fear one or more 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.

(B) You have to be transported to a hospital, and you are admitted to a faith-based institution that refuses to honor your wishes.

(C) Even the "you" whom you may someday become can oppose your wishes. (Note that the new, future incapacitated "you" can be called your "**now-self**," while the past, capacitated "you," who completed your Natural Dying Living Will can be called your "**then-self**.")
While your "now-self" may not be able to talk, he or she can still grunt and point to the food and fluid placed nearby, so that most to all observers would conclude that your "now-self" desires spoon-feeding **to continue**…
A conflict then arises because you will have reached a condition for which your "then-self" clearly and consistently expressed the wish for spoon-feeding **to stop**.

(D) One or more third parties observe you receive spoon-feeding from a caregiver. They point out that you open your mouth and swallow with **no** resistance. They argue that your (apparent) willingness means your "now-self" changed your mind so that spoon-feeding should continue.

(E) A third party claims it is illegal or immoral to stop spoon-feeding since it is "basic care," not "medical treatment." Some third parties often add that living wills do not cover "basic care," which must always must be continued, and this includes spoon-feeding.

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(F) Your currently active proxy/agent does not advocate effectively for your end-of-life wishes, but will not step down to allow a designated alternate to better serve you. But going to court to replace your currently active proxy/agent can take a long time and is often expensive.

(G) You need medications to prevent you from hurting yourself or others, or to relieve your mental anguish. But your physician must wait to give you the medication you need, until a competent authorized person signs the necessary consent form.

(H) You want to live where you are, until you die. But after facility administrators learn that your living will requests Natural Dying, they ask you to move out because they do not want patients to die "that way" on their watch.

(I) Your doctor recently signed a "Physicians Order for Life-Sustaining Treatment" form. But it conflicts with your Natural Dying Living Will, whose previous instructions you still want. A conflict arises if the law in your state mandates that the most recently signed form prevails.

(J) You want total relief from all types of unbearable pain and suffering. But your physician fears others will criticize him/her for committing "slow euthanasia," or for not following this ethical guideline promulgated by the American Medical Association: "Palliative Sedation is **not** an appropriate response to suffering that is primarily **existential**." But you want relief from any type of suffering that is "severe" enough—using sedation, if no other means can provide relief.

(K) An anonymous third party alleges that withdrawing spoon-feeding is elder abuse. So he or she requests an investigation, which can prolong your dying while you are suffering—even if a judge eventually rules that your wishes should prevail. Often this occurs in an institution where any one can anonymously request an investigation.

(L) As a consequence of (J), above, an administrator or clinician in your institution obtains a Temporary Restraining Order so that even your next-of-kin, other loved ones, and legally designated proxies/agents cannot take you to the privacy of your home.

(M) 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 organization requires them to **always offer** you food and fluid. A conflict can thus arise that focused on the word "offer."

(N) You reside in a nursing home or memory care unit whose medical director is a member of The Society for Post-Acute and Long-Term Care Medicine (AMDA)—the professional organization that includes over 5000 physicians who care for patients in nursing homes and assisting living facilities. In March, 2019, this society adopted their Ethics Committee's recommendation to continue "comfort feeding" until your "now-self" either **refuses** to be spoon-fed, or seems

distressed by the act of spoon-feeding—even if your advance directive (living will) previously expressed the exact opposite wish. Their reason is paternalist: to provide what—in their opinion—is the "best interest" of the "now-self" patient in front of them

Attaining the best interest is subject to potential flaws in interpreting your feeding behavior. (A) Your current ability to function is so diminished that you cannot manifest behavior that shows you want to refuse—even though your "then-self" would want others to allow you to die. Or (B) Your physician thinks the act of feeding is causing your distress, but something else is actually causing it, which could be treated if recognized. But instead of doing a thorough evaluation, your physician follows the new, "ethical" protocol: He or she stops "comfort feeding" and allows you to die. But the "then-self" would consider this act premature because—if your problem were treated—you would still want to live.

Why this is unique:

Most advance directives assume that if the planning principal clearly states "what" specific interventions are wanted "when," then their future physicians will (automatically) honor his or her wishes. In contrast, **Strategic Advance Care Planning** considers a clear and specific living will as *necessary but not sufficient*; as a good beginning, but not enough to expect success by itself. Even if you have clearly, consistently, and convincingly expressed your end-of-life wishes, if you lack effective strategies to make sure others fulfill them, you may not attain your end-of-life goals.

Step 5 completes the "Best Strategic Plan" that adds to the "Better Diligent Plan." Infrequently, Step 5 is completed after the "Good Initial Plan" on a case-by-case basis. Example: a patient who suddenly became too ill to generate a second Natural Dying Living Will online or to engage in a video-recorded interview.

Step 6: Store all your forms and videos in a registry so that clinicians and appropriate others can retrieve them readily.

How it works:

This optional step is an invitation to use our national registry, **MyLastWishes.org**, to store all your Strategic Advance Care Planning forms and videos. (Either you or we can upload them.) You will receive a laminated business-sized **MyWCard** whose barcode clinicians and appropriate others can scan using their cellphone or tablet to readily retrieve your forms and videos. You will also receive barcodes on sticky labels to paste on your **POLST** form, driver's license, health

insurance card, etc. Your forms and videos can also be retrieved on a computer if the person knows your basic relevant demographics.

You can optionally record 3 or more short videos that inform emergency first responders precisely what you want at various phases of your life. A common set of examples:

(A) *Now,* you want Cardiopulmonary Resuscitation (**CPR**).

(B) *Later, if you become very sick,* you will want Do Not Attempt to Resuscitate (**DNAR**).

(C) *If you reach a condition that you previously judged "severe enough suffering,"* you will want to implement DNAR plus Natural Dying (**DNAR + Natural Dying**).

When first responders or other healthcare providers scan the 2-dimensional barcode, your menu can be set so the appropriate video will automatically play.

Important note: Your proxy/agent is responsible to make sure that only the appropriate POLST form and video for emergency medical personnel are available. (We can offer suggestions on how to accomplish this.)

BENEFIT:

A relevant fact: the best forms, videos, and strategies can serve you only if your physicians have access to them when they may honor your requests. Step 6 provides strives to make this possible. You can keep your **MyWCard** in your wallet at all times (in case of an emergency). If someday, you become seriously ill, you can wear the card along with a signed POLST form, and you can add a Medallion (metal dog tag). In many states, emergency first responders are legally mandated to respond to standard messages on approved Medallions. If you want Natural Dying, one specific physician order is particularly important so that your dying is **not** prolonged: "NO IV or fluids by any route."

Why this is unique:

Some registries operate primarily in one state. Some organizations store only short (90-second) videos but not long videos of your complete living will. (The average length of a Natural Dying Living Will from Step 4 is about an hour long.) Few registries offer automatic streaming. We know of no other registry that includes all these features.

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Note: If you do not need all the features of Step 6, there may be other online registries that can provide an adequate service. Also, if you someday become bed-bound, and your medical chart is down the hall in an institution, you may not need Step 6 at all.

Want more information?

➔ **Website:** www.caringadvocates.org

➔ **VIDEO:** "Living with Advanced Dementia--What is it really like? Feb 4, 2017" A 14–minute glimpse of why Advanced Dementia is considered among the most cruel, most burdensome, and most prolonged of any terminal illness—for patients, loved ones, and caregivers. youtu.be/jnZOLOliDwQ

Want to try an excerpt first?

➔ Preview our online *patient decision aid* that fully explains our approach and make decisions about 12 (of the 50 conditions), with no obligation at: www.surveymonkey.com/r/BeginToPlan

➔ If you are concerned about a relative who has already reached the stage of advanced dementia, but whose living will is ineffective or does not exist, you can learn about (and even begin) our other protocol, **Now Care Planning**, by going online here: www.surveymonkey.com/r/Now-Care-Planning-for-Dementia

The costs for each step and the entire bundled package
are posted on the website, CaringAdvocates.org.