Six Steps to Strategic Advance Care Planning

➔ The goal of **Strategic Advance Care Planning** is a **private**, **peaceful**, and **timely dying**[1] and to feel peaceful about your plan *now*. Confidence that your plan will succeed—that others **will** honor your wishes after you no longer can speak for yourself—means you will **not** consider premature dying as the only "sure way" to prevent your being forced to endure an unwanted prolonged dying with suffering.

➔ The **Six Steps** let you clearly state **what** treatment you want **when** (condition). Some **strategies** are designed to motivate your future physician to write the orders you will need. Other strategies are designed to prevent *anyone* from sabotaging your goal.

We recommend you complete all six steps. But you can complete just one, if you wish.

Step 1: Complete your "Draft" of your "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[2] by easy-to-understand words and a line drawing. Together, they strive to comprehensively reflect what people dread most about being forced to endure a prolonged dying in advanced dementia and other terminal illnesses.

You can complete Step 1 on your computer, tablet, or cell phone.[3] You 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 try to keep you alive as long as possible.

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[1] This *patient decision aid* can also be used by those who want to live as long as possible, regardless of suffering.
[2] Conditions are described in terms of **what others can observe** (outside) and **what patients feel** (inside). There is **no** implied correlation between any condition and one (or more) diagnoses. Example: A person may have irreversibly and completely lost the ability to respond to others. The cause could be total paralysis due to ALS or a stroke; severe cognitive impairment from physical or chemical trauma; or advanced dementia. Living wills do **not** need to identify what caused this loss of function. Living wills need only to describe the result, for you to consider. Your task is simply to judge each condition if it will, or will not, cause **severe suffering**.
[3] The version of cards printed on cardboard can be spread out on a desk or a kitchen table.

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If you answer is "Yes, suffering from this condition will be severe enough," then others can allow you to die of your underlying disease by implementing **Natural Dying**. This intervention can be effective even if you have "**No Plug to Pull**"; that is, even if sustaining your life does not depend on any high-tech medical treatment because you only need help with spoon-feeding.

The criterion of **severe suffering** may be more **compelling** than criteria used by other living wills to answer the "**When Question**." Examples of other criteria are: reaching a stage of disease; inferring if your feeding behavior is resistant; applying the laudable, but vague "Principle of Proportionality"; assessing your "Quality of Life" is very low; and, judging you are living in a state of "Indignity." Some people worry about the last two.[4]

Your advance treatment decisions generate your **Natural Dying Living Will**. This form strives to be clear and specific to minimize ambiguity and to reduce conflict when others try to interpret **what** you want, and **when**. The intervention **Natural Dying** withdraws assistance by another's hand with hand-feeding and hand-hydrating, but it *never withholds food and fluid*. Instead, it includes the physician order, "Place food and fluid in front of the patient and within his or her reach." For Natural Dying be **effective**, those in authority must **accept** it. So 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 (by the cards and by optional links to 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 in a comprehensive, compelling, and acceptable way so your future physician(s) and others will honor your specific requests.
➔ **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 for **yourself**.[5]

Why this step is unique:

➔ To our knowledge, this living will includes far more conditions than other living wills—about 50, compared to others that typically have 6 or fewer.
➔ No other living will insists on "**severe enough suffering**" after broadening the concept of

[4] Many worry about the last two criteria because they could begin a *dangerous slippery slope* that might lead to this disaster: Granting some people the authority to judge whether the lives of others *are*, or *not worth living*.
[5] In contrast, traditional advance directives empower proxies/agents and expect them to make current treatment decisions on behalf of the incapacitated patient using their substituted judgment.

suffering as the criterion for "when." Suffering includes: physical pain and suffering; emotional or psychic suffering; existential suffering (meaning in life and fear of dying); disruption of one's life narrative; and not being able to spare loved ones from various types of suffering.
➔ No other living will offers a way for physicians to answer the "When Question" so there is **no** need to assess your current suffering. Pragmatically, when "that time" may have come, physicians must only answer: "Has my patient met the clinical criteria of at least one **condition** that s/he **previously judged** would cause **severe suffering**?"

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

How it works:

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

BENEFIT:

The review of your "Draft" Natural Dying Living Will asks if your decisions seem **consistent** with each other, and if they are **credible**, **clinically appropriate**, and conform to **generally acceptable medical practice**. If your decisions seem **deliberative**, it will easier for your proxy/agent to motivate your future treating physician(s) to write orders that honor your end-of-life wishes.[6]

Why this step is unique:

To our knowledge, no other organization provides comments and discusses "Draft" responses with planning principals. We have over seven years of experience in helping patients consider the best decisions for their future incapacitated selves. People typically change between 2 and 12 decisions.[7] Yet planning principals often feel these few changes were important for them to feel at peace now; that their living will reflects what they *really* want.[8]

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[6] Subsequent steps can allow you to demonstrate that, as you made these life-determining decisions for your future self, you were not only diligent, deliberative, but also **consistent over time**.
[7] 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). http://youtu.be/qA0TQS1Pmwk .
[8] This step is **optional**, but strongly recommended. If you are satisfied with your Natural Dying Living Will, or not worried about future challenges and obstacles to honoring your end-of-life wishes, that's your choice. Whatever your reason, we can promptly email you a printable PDF of your Natural Dying Living Will that omits the word, "Draft." You can make this form legally valid if you print it, sign it, and have it appropriately witnessed or notarized.

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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 subsequent thinking, reading, viewing of instructional videos, and discussions with family members, proxies/agents, and other 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 final changes. Then we will send you by U S Postal Service, your "Final" Natural Dying Living Will. This will be printed on heavy stock color paper.[9] To make it legally valid, you can sign this form and have it witnessed or notarized.

BENEFIT:

This step gives you the opportunity to demonstrate that you made your difficult, possibly life-determining decisions in a diligent and deliberative way, and that your decisions were consistent over time.[10] In addition to reflecting your decisions, the "Final" Natural Dying Living Will incorporates strategic wording to motivate your future physician(s) to honor your wishes. Example: Physicians who ignore your wishes risk losing their legal immunity and a lawsuit.

Why this step is unique:

To our knowledge, no other organization offers planning principals **two opportunities** to make advance treatment decisions as they complete their living wills.[11] Nor does any other living will "warn" physicians about the possible consequences of ignoring 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 cannot

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[9] You will also receive three 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**.

[10] Although the word "Final" modifies "Natural Dying Living Will," you can always change your decisions if you still have mental capacity. Your revised version can be called your "Updated Final" Natural Dying Living Will.

[11] Other living wills typically require one or a few checks from a choice of boxes or a signature at the bottom.

travel, or if you live far from our network of counselors, you can use our secure, private, HIPAA-compliant Internet video program. We can send you the finished video on a thumb drive, upload it to YouTube using its privacy settings, and store it on our 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 see that you had **capacity** (were mentally competent) to make these decisions if you demonstrated that: you **understood** and **appreciated** the consequences of the two treatment options (Treat & Feed *versus* Natural Dying), and you used logical **reasoning** to make a set of treatment decisions that you **expressed** with **consistency**.

Step 4 is especially important for patients who have a diagnosis or condition that may affect thinking, memory, or judgment. Examples include: Mild Cognitive Impairment, early dementia, brain trauma or tumors, high doses of medications to treat pain, and liver or kidney failure. Your interviewing counselor can express a clinical opinion about capacity that carries more clinical and legal weight than a lay person's opinion regarding "sound mind." 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 others 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 you have spoken for yourself. If someday, you lose capacity and cannot speak for yourself, others can view your video to learn and to appreciate **what** you *really* wanted, and **why**.

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 as fully as possible, the planning principal's end-of-life wishes. Nor do other organizations structure the interview so a counselor can conclude with a clinical opinion regarding your decision-making capacity.

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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 two documents, the **Natural Dying Agreement** and the **Natural Dying Affidavit**. They include a comprehensive set of legal/medical/logistical strategies with instructions about who needs to sign. To become a member of your Decision Committee, an individual must sign a page that makes the durable power of attorney for healthcare decisions a "bilateral contract." As your currently active proxy/agent or alternative proxies/agents, they must agree 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, so they can be replaced by another member of your "Decision Committee" if other judge their behavior as currently active proxy/agent is *ineffective* (as the Natural Dying Agreement defines).

The Natural Dying Affidavit lets you swear in front of a notary that your declaration is "true and correct." This makes it possible a judge to admit the Natural Dying Affidavit as evidence. Ironically, this strategy may prevent the need to go to court. Here's why: Opponents may read your Affidavit and fear a judge will honor your wishes so instead of going to court, they will no longer challenge your wishes.

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 after you reach a condition that you judged causes **severe enough suffering** to want others to implement Natural Dying, and want others **to stop spoon-feeding**:

(A) You fear one or more relatives might try to influence your physician not to honor your end-of-life wishes based on their different (perhaps religious) beliefs.

(B) Even the "you" whom you may someday become can oppose your wishes. (Note: Below, the new, future incapacitated "you" is called your "**now-self**," while the past, capacitated "you," who completed these Steps including your Natural Dying Living Will, is called your "**then-self**.") While your "now-self" cannot talk, your "now-self" can still grunt and point to the food and fluid placed nearby. Observers conclude your "now-self" wants spoon-feeding **to continue**…

But the condition you have reached is one your "then-self" wanted spoon-feeding **to stop**.

(C) One or more third parties observe you receive spoon-feeding from a caregiver. They point out how you open your mouth without resistance. They argue your (apparent) willingness means your "now-self" changed your mind and then claim you now want spoon-feeding to continue.

(D) A third party claims it is illegal or immoral to stop spoon-feeding since it is "basic care," not "medical treatment."

(E) Your currently active proxy/agent does not advocate effectively for your end-of-life wishes, but will not step down so an alternate can better serve you (for any reason). This may be more likely to happen if your first choice proxy/agent is not available. But going to court to replace your currently active proxy/agent can take a long time and cost a lot of money.

(F) You need medications to prevent you from hurting yourself or others, or to get relief from mental anguish. But your physician cannot give you medication until a competent person signs a consent form.

(G) 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.

(H) 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.

(I) 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 of the American Medical Association: "Palliative Sedation is **not** an appropriate response to suffering that is primarily existential."

(J) A third party petitions a hearing in a court of law. Although your "then-self" was informed that your Living Will and other forms were legally valid, and they still are—the opposing third party argues that the judge should not admit these forms into evidence since you did not swear an oath that they were true and correct, when you signed them.

(K) An anonymous third party believes that withdrawing spoon-feeding is elder abuse and requests an investigation that can lead to your prolonged dying and suffering—even if your wishes eventually prevail.

(L) Your physician, or the facility in which you reside, refuses to honor your Natural Dying Living Will when your proxy/agent requests, refuses to let your proxy/agent or loved ones take you

home, and states they will request the use of force, if necessary, to prevent your proxy/agent or your loved ones from trying to take you home, as per the results of the Adult Protective Services investigation.

(M) The legal department of the facility where you reside points out that the statute in your state, or the regulations of Medicare or another organization requires them to always offer you food and fluid.

(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). This professional organization 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.

But your current ability to function is so diminished that you cannot manifest behavior that shows your refusal, yet you still want to die.

Another possibility: Your physicians think your distress is caused by the act of feeding, but something else is causing your distress and it could be treated if recognized, but this takes a thorough evaluation. Your AMDA physician might follow the "ethical" protocol to stop "comfort feeding" that causes you to die prematurely; that is, before you would want to die.

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 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; as an ample statement of wishes, but lacking effective strategies to make sure others will fulfill them. Example: A physician may consider your expressed wish to stop others putting food and fluid in your mouth if you meet the clinical criteria of a certain condition as just one factor to consider. Other factors, such as the ones listed above may seem more important to physicians or third parties.[12]

[12] Success seems likely on its face, but to our knowledge resolving these conflicts have not been tested clinically or in court. Yet one goal that defines success is a dying that is **private**, where conflicts that arise are resolved at the bedside. While no one meant to keep successes secret, it is not likely that we, or the public, would have been informed about it.

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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 join our national registry, **MyLastWishes.org**. You (or we) can upload all your Strategic Advance Care Planning forms and videos. You will receive a laminated business-sized **MyWCard** that has a barcode that clinicians and appropriate others can scan using their cellphone or tablet to readily retrieve your forms and videos. Clinicians can also input some of your relevant demographics in their computer.[13]

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,* Do Not Attempt to Resuscitate (**DNAR**).
(C) *If you reach a condition that you judged "severe enough" to implement 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.[14]

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 makes 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 perhaps 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 treatment refusal is important so 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 Natural Dying Living Will from Step 4 is an hour long.) Few registries offer automatic streaming. We know of no other registry that includes all these features.

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[13] You will receive copies of your barcodes on sticky labels that you can paste on your **POLST** form, driver's license, health insurance card, and other places.
[14] It is your proxy/agent's responsibility to make sure only the appropriate POLST form is available.

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Want more information?

➔ **Website:** www.CaringAdvocates.org/acp/

➔ **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. https://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.

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Cost and approximate times to complete each step:

Step 1, Draft Natural Dying Living Will: Cost: $45. Time: 45 to 75 minutes. Total time will be 12 minutes longer if you view the recommended 14-minute instead of the 2-minute video to learn what it is like, for patients and for their loved ones, to live with advanced dementia.

Steps 1, 2, and 3 with an introduction to Step 4: Cost: $125. Time: 10 minutes to read and discuss the comments about your "Draft." Extra reading and video viewing may be recommended. Another 30 to 60 minutes to complete your "Final" Natural Dying Living Will.

Step 4, Interview recorded on video: Cost: Could be "zero" if you ask your proxy/agent, friend, or loved one to conduct the interview.[15] If you ask Dr. Terman or one of his trained clinical colleagues, the cost will be between $150 and $400 per hour. Interviews typically last between three-quarters of an hour, and one and a half hours.

➔ Ask our staff to estimate what portion of our fees your health insurance policy is likely to pay, if one of our trained clinicians interviews you.

Steps 1 through 5, including the Natural Dying Agreement and Affidavit: $195. Time: Depends on how quickly others sign their respective forms.

Step 6, national registry to store your forms and videos: Cost: Membership in MyLastWishes.org depends on the duration of membership you choose. Examples: $45 for one year; $195 for life. Ordering a Medallion (metal dog tag) so that emergency first responders will honor your CPR/DNR wishes, costs about $80. Time: half hour to register and complete the form to indicate the information you want on your **MyWCard** (and Medallion).

[15] Having a counseling healthcare provider conduct the interview is highly recommended for planning principals who currently have a diagnosis of a brain disorder that affects thinking, memory, or judgment. Examples: Mild Cognitive Impairment, early dementia, brain trauma or tumors, high doses of medications to treat pain, liver or kidney failure. A clinician's opinion about capacity can carry more clinical and legal weight than lay person's opinion regarding "sound mind." Both can state the patient made her decisions voluntarily.