Can Advance Care Planning for Late-Stage Dementia Effectively Reduce How Long and How Much You Suffer?

Yes, If Your Strategies are Moral

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Plan Now, Die Later—to Live Longer

Because mercy killings (loving homicides), suicides, and suicide attempts all occur. And they preoccupy the minds of the suffering even if they don’t.

Why? Because planning principals have this desperate fear: others will sustain their lives and thereby cause them severe suffering personally and cause their loved ones huge burdens.

Having confidence that your advance care planning efforts will succeed can allow you to dismiss this worry, and thereby prevent premature dying, so you can enjoy life as long as you can.

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

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

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

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

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

Her suffering can become chronic because casual observers—including many professionals—**dismiss it without diligence or compassion** by this judgment: “**She’s not suffering. She’s just sitting there.” This dangerous non-sequitur** fallacy equates outward calm—which is actually pathological withdrawal—with inner peace, if Sarah is actually experiencing profound depression as a result of her existential isolation.

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

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

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

The elusive holy grail of living wills

One essential characteristic of living wills — to ensure patients receive goal-concordant, end-of-life care — which is both their ultimate purpose and their most formidable challenge.

This goal has been so difficult to achieve that several leading experts in the field of ACP have publicly acknowledged they are abandoning it.

And some experts instead reassigned other roles to living wills; such as “improving caregiver outcomes.” Others experts are waiting for new tools to emerge. Perhaps you’ll see one such tool, today?

The goal for living wills:

Want = Get

Without effective moral strategies:

Want ≠ Get

What threatens your attaining your end-of-life goals?
Physicians and others trying their best to help you as THEY feel is right.
Physicians can interpret your living will “If . . . Then” statements as REQUESTS. . . .

and then behave as if THEY have authority to consider your REQUESTS along with other factors based on THEIR clinical judgment and experience. So, the result may NOT HONOR the orders you need. This is paternalism.

Three challenges to attain a timely and peaceful dying:

Challenge #1 is based on the natural cause of the disease.

Challenges #2 and #3 are based on the controversial nature of the solutions proposed to overcome them.

Challenge #1: Losing decision-making capacity (DMC) years before they die, which makes patients unable to:

Speak for themselves just when it's most important

State what treatments they do or do not want then

Revise their living wills, so they are acceptable and effective

Why is advanced dementia so challenging?

Challenge # 2: “No plug to pull.”

Patients may not depend on high-tech treatment to sustain their lives—that can be withdrawn or withheld, to allow a natural dying.

Note that traditional living wills are silent regarding the right to refuse assisted oral feeding and hydrating—in advance.

So, many patients live for years; some, even a decade.

Almost all “dementia-specific” living wills request cessation of assisted feeding.

Clinical and moral arguments for Natural Dying:

For the unique circumstances of this phase of life, feeding ≠ loving.

At some point as dementia progresses,
assisted feeding becomes:

Unnatural (patients would not feed themselves),

Forced (unwanted, per living will statements),

and **unethical** ➔

Force Feeding Violates the Four Principles of Bioethics

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

But “Dementia-Specific” living wills have flaws that could cause dying to be either premature or prolonged.

In 2022, *BioMed Central Medical Ethics* published our critical review of new dementia-specific living wills. All had at least one of 24 identified flaws—in process, content, inherently, and/or by lacking strategies

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

Caring Advocates’ **Natural Dying Living Will** includes this treatment of last resort

Natural Dying (ND) withdraws others’ assistance with oral feeding and hydrating if you reach a condition that you previously judged (during ACP) would cause irreversible, severe suffering. (Work began in 2006)

The protocol requires the second order, "**Always place food and fluid within patient's reach**," which is designed to uphold the highest legal, ethical, and **moral** standards. (This is unique.)

Since food and fluid are always offered, one can argue that the goal was not to hasten dying and the patient died of his/her underlying disease.

Example one: a living will states its intended audience is patients with early dementia, but requires a reading comprehension of **grade 14** (college sophomore).

Example two: no living will includes a strategy to resolve this "Classic Conflict“: The past planning principal wanted assisted feeding **to cease** *versus* the current dementia patient wants assisted feeding **to continue**.

➔ Which patient should physicians/providers honor?
➔ Can the order overcome prevailing statutes?

Strong words are inadequate; legal actions are required.

Challenge #3: The patient can still eat and drink

Being able to independently self-feed and self-hydrate, an Activity of Daily Life, is usually positive.

But for patients living with advanced dementia, it can be a liability—if it prolongs suffering as well as living.

How does this happen? The way dementia progresses varies widely among patients. For some, the impairment of mental functioning progresses faster than losing physical capabilities.

Important: It is not legal, ethical, or moral to withhold food and fluid because it can be viewed as **euthanasia**, which is **illegal**.

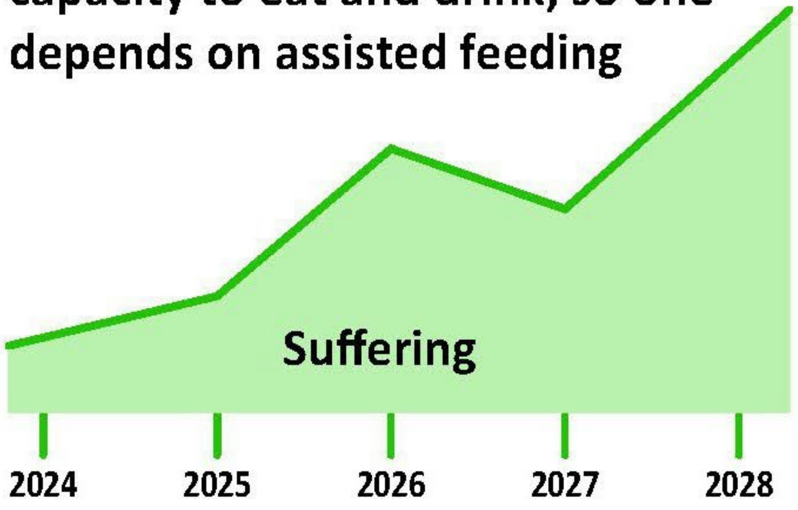
So, treatment that ceases assisted feeding cannot work for patients who do not depend on assisted feeding.

These patients are living in the **Dementia Gap**.

They need another treatment of last resort. Patients must sign a consent that they agree to its risks: (A) their consciousness may not return before they die and (B) they may die sooner.

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



Has capacity, articulate
Knows what he wants

Lacks capacity, inarticulate
May not recognize food and fluid

The second treatment of last resort

Moderate Anesthesia (MA) provides sedation to unconsciousness but only if (1) you are living in the “Dementia Gap”; (2) your suffering is exceedingly severe; and (3) your suffering cannot be relieved by less sedating treatments.

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

Adding “Respite Sedation” to the protocol helps prove your physician’s intent was to relieve suffering—not to hasten death. The extensive informed consent also distinguishes **MA** from classic "palliative sedation to unconsciousness."

To be moral, physicians and patients must focus on **INTENT**

- INTENT **cannot be to hasten patient’s dying**, based on clinicians’ documents and behavior
- INTENT **must be to relieve patient’s suffering**
- Both during advance care planning (ACP) and during implementation
- Your physicians’ documents and behavior, and yours, must be consistent with focusing only on suffering

Double Effect: a workable Moral Principle

If the intent is good, it is moral to commit an act
whose bad outcome was foreseen as possible,
IF the bad outcome was not intended, and
IF this “bad” is not the means to achieve the “good.”

Example of a foreseen possibility: a side effect of treatment is to possibly cause the patient to die sooner.

It is never moral to kill someone in order to relieve their suffering. Exceptions are common in practice: 1 of 20 dying Canadians.

Why morality matters

Treatments of last resort are controversial. If life ends, it’s irreversible. All concerned want to be sure that it’s the right act at the right time.

Advance care planning cannot be successful unless the prescribing physicians/providers and their institution agree to implement the orders patients need.

Those in authority must accept the treatment, which often includes requiring being able to view the treatment as moral.

The Judged Intensity of Suffering that a Condition Would Cause Determines →	Which Treatment the SACP Protocol Prints in Your “Natural Dying Living Will”
Exceedingly severe suffering	**MA-POLST** (Moderate Anesthesia)
Severe suffering	**ND-POLST** (Natural Dying)
Tolerable suffering	**SLT-POLST** (Selective/Limited)
Mild or No suffering, but terminally ill	**CPRL-POLST** (1 last CPR, then SLT)

Treatment Option	Brief Description
Moderate Anesthesia (MA-POLST): Indicated if suffering is refractory to all non-sedating treatments or achieving relief is urgent, especially for patients who can still eat and drink without another’s assistance	Use sedating medications to directly reduce the source of suffering if possible; if not, reduce consciousness so patient is unaware of (dissociates from) suffering + DNR + Comfort-Focused Treatment
The **goal/benefit/purpose** of **MA**: To prevent unwanted, prolonged, exceedingly severe suffering in any terminal illness.	

It’s easy to use My Way Cards—2

Judgments are based on **patient's lifelong values and treatment preferences**. Examples:

“I do not want to burden my loved ones with my terminal illness, especially if I can’t appreciate their sacrifices and expensive care will not benefit me since I will not be able to enjoy living.”

“I do not want to be connected to a breathing machine or feeding tube until I die.”

Part Three:

1. My Way Cards: an easy-to-understand “patient decision aid” to appreciate what it can be like for patients and their family members to live with conditions of advanced dementia

2. Three other strategic documents support or actualize your Natural Dying Living Will

3. How the Implementation Phase usually begins

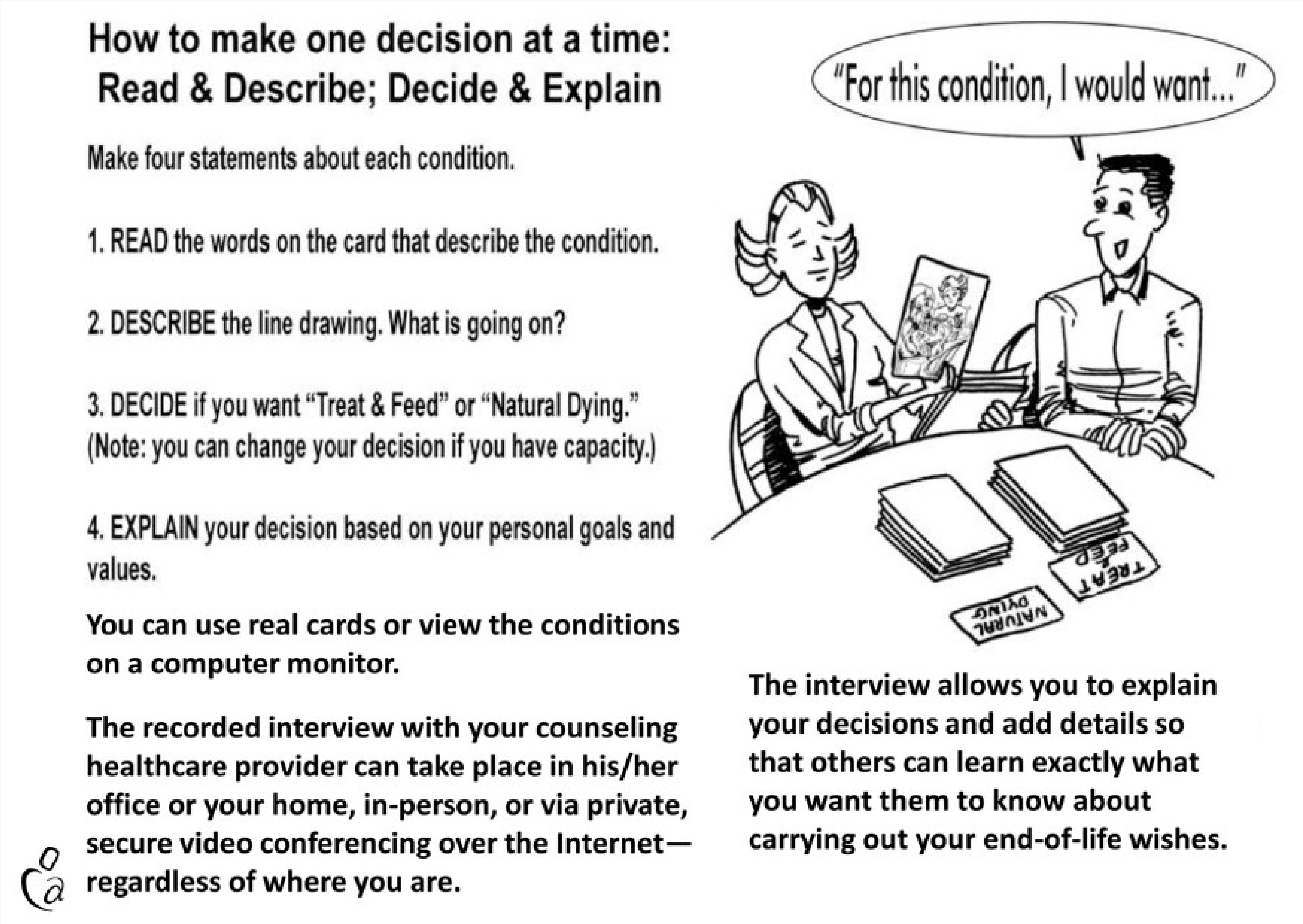
Record a semi-structured interview on video

Four Tasks:

READ

DESCRIBE

DECIDE
EXPLAIN



How to make one decision at a time: Read & Describe; Decide & Explain

Make four statements about each condition.

1. READ the words on the card that describe the condition.
2. DESCRIBE the line drawing. What is going on?
3. DECIDE if you want "Treat & Feed" or "Natural Dying."
(Note: you can change your decision if you have capacity.)
4. EXPLAIN your decision based on your personal goals and values.

You can use real cards or view the conditions on a computer monitor.

The recorded interview with your counseling healthcare provider can take place in his/her office or your home, in-person, or via private, secure video conferencing over the Internet—regardless of where you are.

The interview allows you to explain your decisions and add details so that others can learn exactly what you want them to know about carrying out your end-of-life wishes.

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

P

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

Severe enough suffering

No suffering

P

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

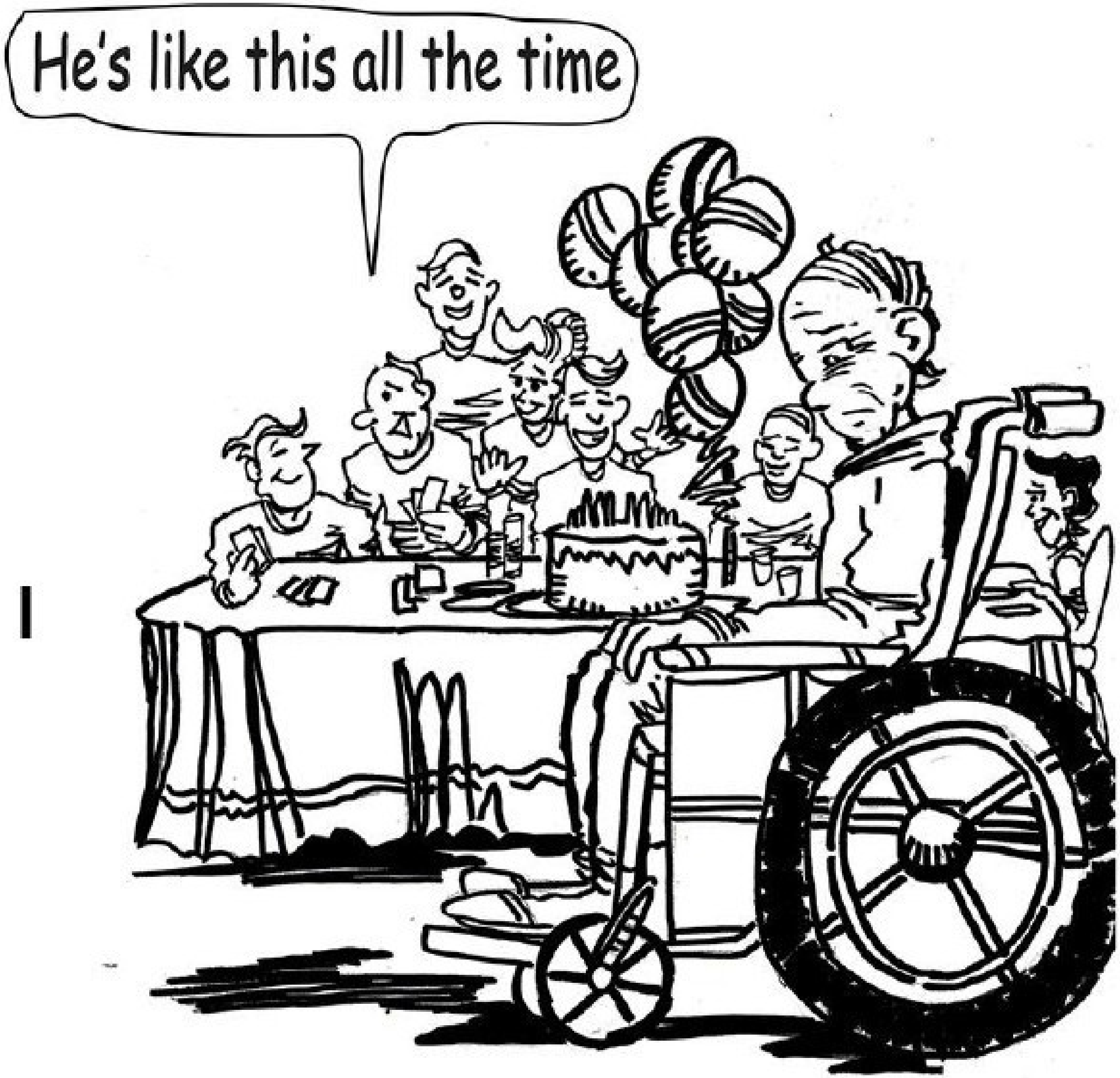
P

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

S

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

S



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

The NDLW is one of four strategic documents. It also includes this “Dear Doctor” warning:

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

Here are all four Strategic documents. The tasks: complete, record on video, notarize (jurat):

1. Natural Dying Living Will (+ persuasive video)
2. Bilateral durable power of attorney for healthcare decisions (includes forming PDC)
3. Natural Dying Agreement (includes strategies)
4. “Future POLSTs” (as many as ten)

Bilateral durable power of attorney includes irrevocable part, if you wish:

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

Bilateral durable power of attorney; Patient Decision Committee: Implementing the LW

During ACP, the planning principal establishes a **Patient Decision Committee.** Its members are responsible to respond to changes in patients' clinical status as follows:

1. Any suspicion the patient may have reached a "qualifying condition" needs to be investigated. If a visit to the patient and a review of the living will indicate this is likely, then members of the PDC meet and vote if the patient's condition does qualify. If they reach a **consensus of substituted judgment**, that will authorize the current agent to engage the treating physician in a "shared decision-making conference" that can also serve as a "POLST Conversation." The clinical treatment plan then may change by replacing the current POLST with one of the other stored "Future POLSTs."

PDC members vote: Does the patient’s intensity of suffering for various conditions qualify them to change to another POLST?

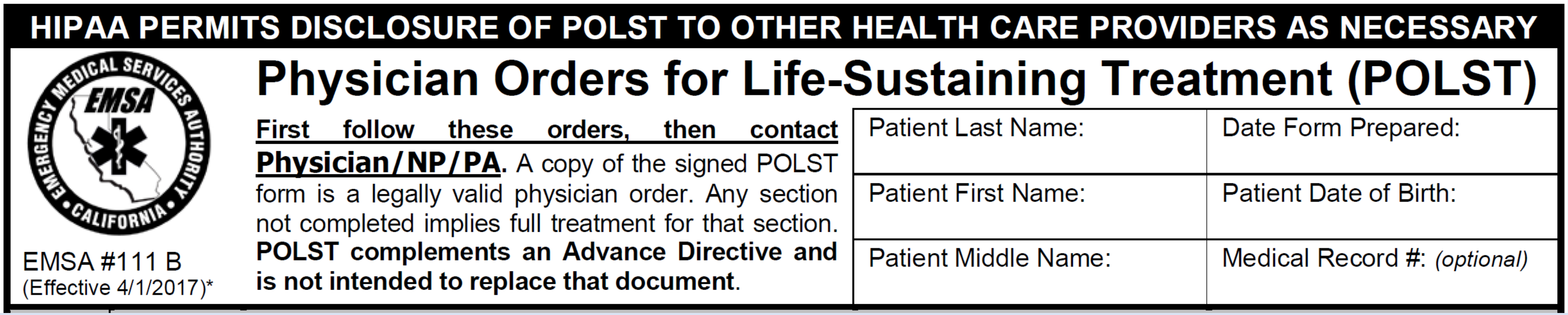
For NOW Care Planning, each decision-maker was asked to use their substituted judgment to opine: “If the capacitated AK of the past had been asked, would she have judged any of these conditions are NOW causing exceedingly severe suffering—which qualifies her for Moderate Anesthesia?						
Summary (Conditions’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

Why POLSTs are effective

Each POLST has an added order: it must be consistent with the patient’s living will.

POLSTs transform what some physicians or providers might consider a “request—if you agree, dear doctor, please”— o the strategic authority of a physician order that matches what patients want in their current condition.

POLSTs avoid conflict when implemented



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 4/1/2017)*

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: *(optional)*

POLSTs could not be clearer:
First follow these orders, then contact Physician /NP/PA.

Why POLSTs are strategically effective

- Immediately actionable (limits time for conflicts to emerge)
- Has the authority of physicians'/providers' orders
- Law/customary practice: requires other providers to follow its orders
- Law/customary practice: applies in all treatment settings

Additional (unique) strategic orders:

- Insists only patients can change POLST, so it is durable/irrevocable
- Insists orders be consistent with Living Will, so it can fulfill goal-concordant care (mission possible!)

Why “Future POLSTs” can be accepted:

Successor clinicians typically rely on their predecessor’s assessment.

This means their clinical responsibility and moral toll are minimized.

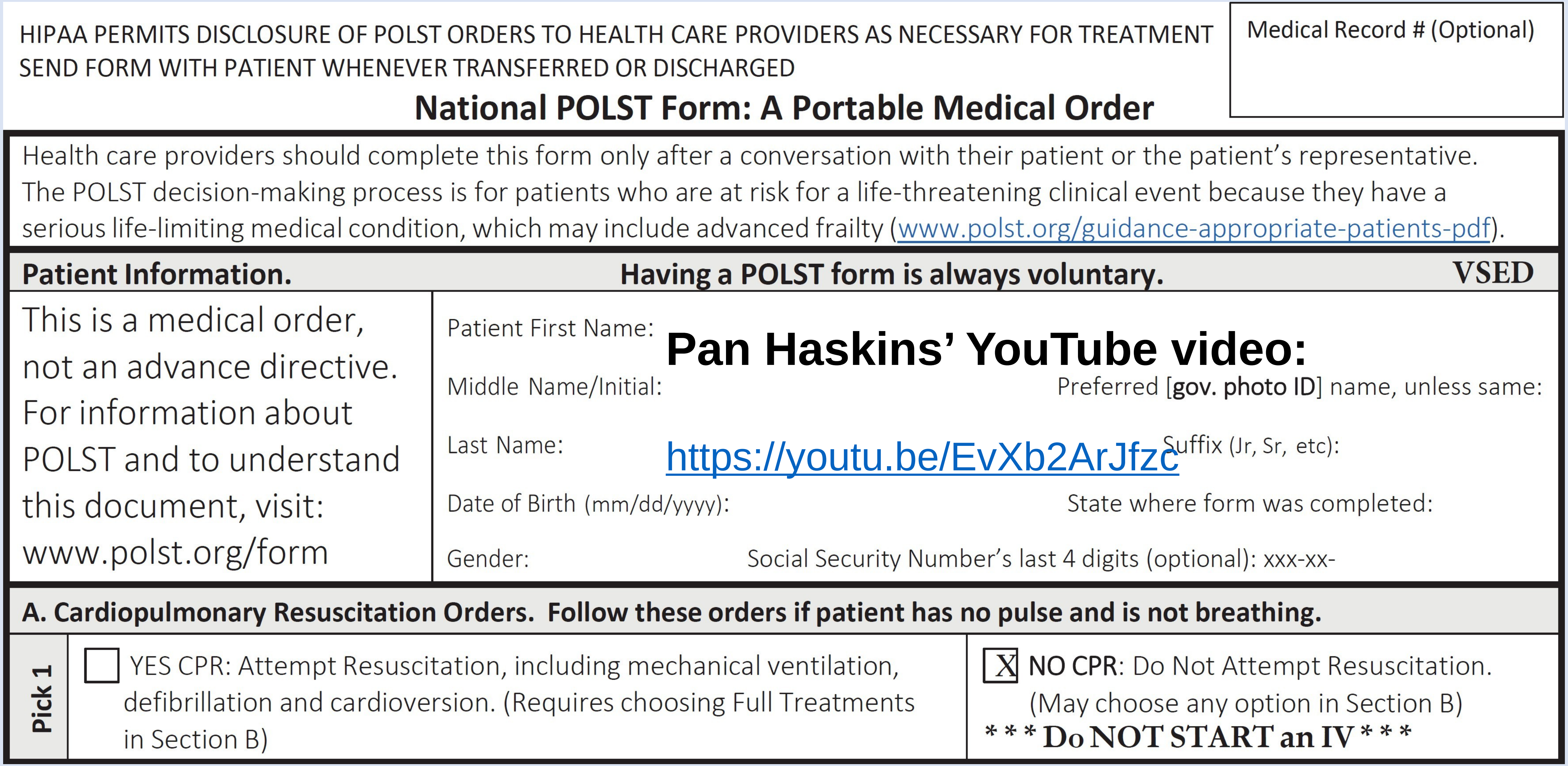
The ACP counselor or physician/provider will have previously held a POLST Conversation recorded on video that the current treating physician or provider can view (along with the patient’s living will video).

The predecessor clinician will have stated in writing that the patient:

1. Possessed **capacity** to complete the two linked documents: their Natural Dying Living Will and their set of Future POLSTs.
2. Carried out these tasks **voluntarily**.
3. There was no suspicion of **undue influence**.

A legal and clinical “insurance policy” for VSED (Voluntarily Stopping Eating and Drinking) that uses the National POLST form

- VSED is often used as alternative to Medical Aid in Dying. It is legal everywhere. But you must have decision-making capacity. (Of course, there are some practical challenges.)
- Once you are asleep, you will not be able to speak for yourself, and your agent may not be able to convince others what you want.
- A temporarily restraining order could put you back to start all over,
- So, others could use your vulnerability as an opportunity to sabotage your end-of-life plans.
- You can prevent this with the authority of physicians’ orders in a POLST and a video on which you explain why you want VSED.



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

Medical Record # (Optional)

National POLST Form: A Portable Medical Order

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

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

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

Patient First Name:

Pan Haskins' YouTube video:

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

Last Name:

https://youtu.be/EvXb2ArJfzc

Suffix (Jr, Sr, etc):

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

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

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

Pick 1

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

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

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

Natural Dying Agreement contains about a dozen strategic arguments based on clinical evidence and case law and statutes. Its currently 42 pages. Here is the Table of Contents (only):

Completing the protocol,
as guided by your ACP counselor of physician/provider, which proceeds at the pace you choose, usually 2 weeks to 2 months.
See the 4-page summary “Overview” and the 25-page “Seven Steps to Strategic Advance Care Planning” details. Here are the 7 Steps:

Strategic Advance Care Planning’s Seven Steps

1. Complete Your Natural Dying Living Will (at your own pace)
2. Revise with Your ACP Counselor (X 3, to be consistent & credible)
3. Form Your Patient Decision Committee (includes agents & others)
4. Record the Testimony of Your Living Will on Video (CCCC*)
5. Add Legally Supported Strategies (to Overcome Challenges)
6. Include Specific “Future POLSTs” (includes ND & MA)
7. Notarize a Jurat to Admit/Prevent Court; Registry for Quick Access

(*CCCC = Clear, Consistent, Convincing, Compelling)

Next is a video excerpt of my interview with Jay 20 months after his wife Karen* died by **Moderate Anesthesia** in September 2023.

She had completed her ACP in 2019 before MA was option.

So, the Patient Decision Committee members used their substituted judgment to decide if she would have definitely preferred MA to ND.

Natural Dying (ceasing assisted oral feeding and hydrating) was not available since she was living in the **Dementia Gap** (could eat and drink) for the last year.

(*In Danish, pronounced similar to Korean)

What we discussed in this part of the interview.
(The complete unedited video is available at this URL: https://youtu.be/IxgHg2I2D_E)

1. How Jay feels **now** about the Patient Decision Committee agreeing that the time had come for Moderate Anesthesia.

2. I explain the broadened concept of suffering: five **sources** and three **types** of suffering; importantly, some are difficult or impossible to observe by a contemporaneous examination of the patient

(continued ➔)

3. Trying to understand Jay’s unanticipated, profound grief:

It included ambiguous loss and grief, which are difficult concepts

The irony: the more functional she was, the more he enjoyed her company and therefore, the greater his loss.

Karen’s ability to eat and drink provided companionship—even without meaningful conversation—which was a big loss.

He also lost his caregiving role that had given his life meaning. As St. Francis of Assini wisely taught: “It is in the giving that we receive.” Being generous can be paradoxical. It can unexpectedly and profoundly enrich the giver. Jay missed being enriched in retrospect—even though caring was a huge burden.

The **Natural Dying Living Will** has a broadened view of suffering: **five sources**

1. **Physical/somatic** (including non-observable pain)
2. **Psychic/emotional** (sometimes, as severe as physical)
3. **Existential** (including “deaths” of important relationships)
4. **Disruption of life narrative** (plus future tarnished memories)
5. **Causing loved ones’ suffering** (four ways above plus financial plus “ambiguous grief” and “bi-directional empathic suffering)

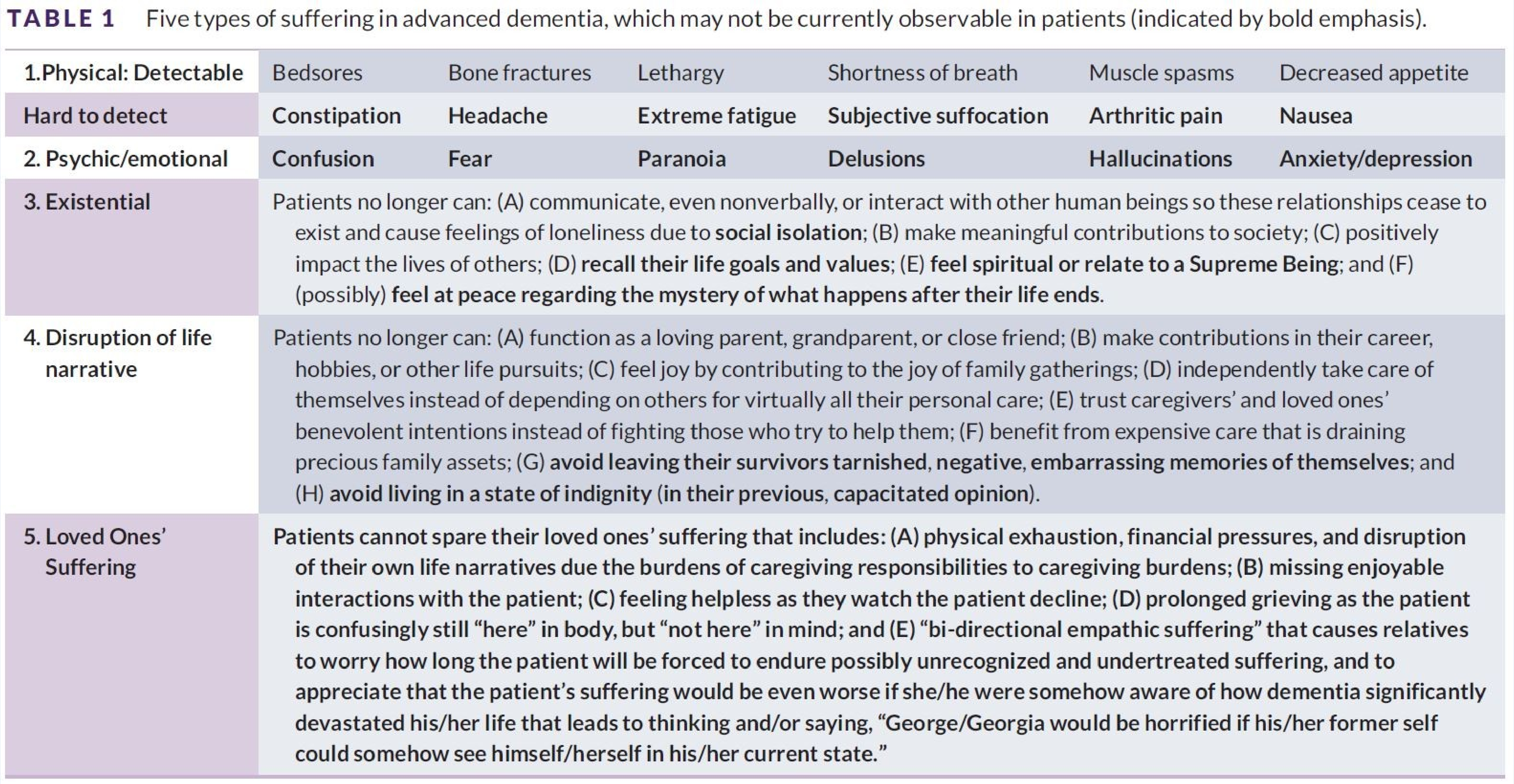


TABLE 1 Five types of suffering in advanced dementia, which may not be currently observable in patients (indicated by bold emphasis).

1.Physical: Detectable	Bedsores	Bone fractures	Lethargy	Shortness of breath	Muscle spasms	Decreased appetite
Hard to detect	**Constipation**	**Headache**	**Extreme fatigue**	**Subjective suffocation**	**Arthritic pain**	**Nausea**
2. Psychic/emotional	**Confusion**	**Fear**	**Paranoia**	**Delusions**	**Hallucinations**	**Anxiety/depression**
3. Existential	Patients no longer can: (A) communicate, even nonverbally, or interact with other human beings so these relationships cease to exist and cause feelings of loneliness due to **social isolation**; (B) make meaningful contributions to society; (C) positively impact the lives of others; (D) **recall their life goals and values**; (E) **feel spiritual or relate to a Supreme Being**; and (F) (possibly) **feel at peace regarding the mystery of what happens after their life ends.**					
4. Disruption of life narrative	Patients no longer can: (A) function as a loving parent, grandparent, or close friend; (B) make contributions in their career, hobbies, or other life pursuits; (C) feel joy by contributing to the joy of family gatherings; (D) independently take care of themselves instead of depending on others for virtually all their personal care; (E) trust caregivers' and loved ones' benevolent intentions instead of fighting those who try to help them; (F) benefit from expensive care that is draining precious family assets; (G) **avoid leaving their survivors tarnished**, **negative**, **embarrassing memories of themselves**; and (H) **avoid living in a state of indignity (in their previous, capacitated opinion)**.					
5. Loved Ones' Suffering	**Patients cannot spare their loved ones' suffering that includes: (A) physical exhaustion, financial pressures, and disruption of their own life narratives due the burdens of caregiving responsibilities to caregiving burdens; (B) missing enjoyable interactions with the patient; (C) feeling helpless as they watch the patient decline; (D) prolonged grieving as the patient is confusingly still "here" in body, but "not here" in mind; and (E) "bi-directional empathic suffering" that causes relatives to worry how long the patient will be forced to endure possibly unrecognized and undertreated suffering, and to appreciate that the patient's suffering would be even worse if she/he were somehow aware of how dementia significantly devastated his/her life that leads to thinking and/or saying, "George/Georgia would be horrified if his/her former self could somehow see himself/herself in his/her current state."**					

The **Natural Dying Living Will’**s broadened view of suffering

Terman SA, Steinberg KE, Hinerman N. Timely dying in dementia: Use patients' judgments and broaden the concept of suffering. Alzheimers Dement (Amst) 2024;16(1):e12527. DOI: 10.1002/dad2.12527

Another perspective: the comprehensive **Natural Dying Living Will** includes **three types** of suffering:

1. Sensation-based

2. Functional-based*

3. Values-based

Notes:

(A) There is some overlap

(B) Suffering from one type could cause suffering of another

*Original authors used the (too lofty) term “flourishing-based”

Before this presentation ends with my interview of Jay, here is a brief description of Caring Advocates’ alternative protocol, NOW Care Planning, which is designed for patients who have reached an advanced stage of dementia without completing an effective living will

NOW Care Planning relies on the efforts of members of the Patient Decision Committee.

Only some strategies can be set in place. Often, they suffice.

To my knowledge, it is the best legal, ethical, and moral approach available.

Each member is asked: “How much suffering would the patient have judged this condition would cause him/her and family members —if asked before losing capacity?”

Then, members discuss and vote ➔

PDC members vote: Does the patient’s intensity of suffering for various conditions qualify them to change to another POLST?

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

Advantages of the Patient Decision Committee:

Emotional support can be important to reduce grief

No one person has to shoulder all existential angst

Accurate treatment decisions by multiple decision-makers is more likely (but not yet proven)

The protocol can help prevent behaviors of a single agent that are based on a conflict of interest

Financial and compassionate concerns

The estimated annual cost of care for patients living with dementia will soon exceed a trillion dollars a year—not accounting for the human suffering of patients and their family members. One person's disease affects the lives of several others. Some family members become caregivers and abandon their professions to keep their relative alive who really would have wanted—and perhaps have stated years ago, if asked—a peaceful and timely dying.

This presentation lacked enough time to cite compelling evidence that much suffering in advanced dementia is difficult to detect. If not detected, it will not be treated. This adds to the many symptoms that are inherently untreatable. (Read Sarah's story near the beginning of these slides.)

Concluding remarks

- Premature dying is tragic. You do not need to sacrifice enjoyable life. You can live as long as you can still enjoy living.
- You need not hasten your dying if the only reason is to prevent "getting stuck" in advanced dementia. There are alternatives.
- One alternative is "Strategic Advance Care Planning."
- Your call to action is: **If you still have capacity, be proactive now.**

- **Plan Now, Die Later—to Live Longer**

For relatives who have reached an advanced stage of dementia without an effective living will and did not add needed strategies, learn more about **NOW Caring Planning**.

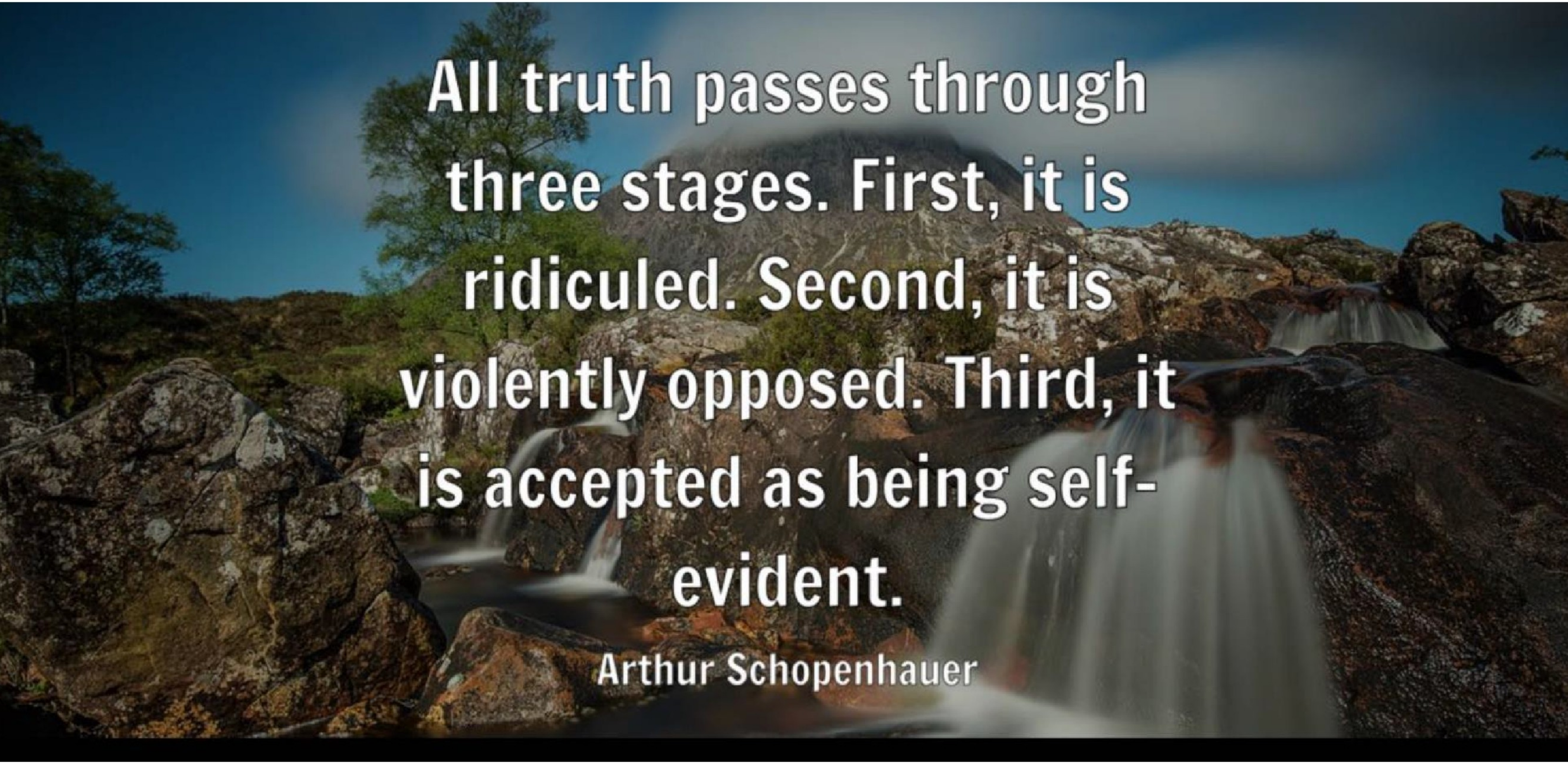
Strategic Advance Care Planning

Make your living will and supporting strategies clear, consistent, convincing, and compelling (CCCC).

Confidence in this program → feel peace now.
Later → receive goal-concordant end-of-life care.

This can be your slogan:

Plan Now, Die Later®—to Live Longer.



All truth passes through three stages. First, it is ridiculed. Second, it is violently opposed. Third, it is accepted as being self-evident.

Arthur Schopenhauer

Contact information

- Drterman@CaringAdvocates.org
- 800-64-PEACE (800-647-3223)
- Text: 760 704 7524
- More information: CaringAdvocates.org website
- New files are at CaringAdvocates.org/newstuff/
- A video of this new presentation will be available soon.

Polling participants’ opinions

The **DDDD**’s of Strategic Advance Care Planning

- Demonstrate: memorialize your testimony on video and swear a oath before a notary so it can be admitted as evidence in court
- Diligent: review your judgments of severity of suffering 3 to 6 times
- Explain/persuade that they are based on your lifelong values
- Deliberative: discuss your decisions with physicians, ACP counselors & others; hold a final “**Deliberative Capstone Review**”
- Decisions for treatment and implemented strategies allow you to feel confident about controlling (as much as possible) how and when you will experience your peaceful and timely dying

The last of the Seven Steps to Strategic Advance Care Planning

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

“Born” in 1969, Living Wills’ limited purpose and format remained unchanged—until now

- Kutner, Luis. Due Process of Euthanasia: The Living Will, A Proposal. Indiana Law J. 1969;44(4):539-54. Available from: https://www.repository.law.indiana.edu/ilj/vol44/iss4/2/
- “A dilemma in the criminal law: when one individual observes another who is suffering from the pain of an incurable disease or a genetic deformation and, motivated by compassion, ends his life, the question arises as to whether he should be regarded as a murderer.”
- What if mercy is the moral motive? There is a difference between the statuary law and practice, where an exception [sometimes] exists.

“Born” in 1969, Living Wills’ limited purpose and format remained unchanged—until now

- “There is a point in the degeneration of our bodies when life loses its value, and we may then be prepared voluntarily to leave the scene to our successors.”
- A patient may refuse treatment which would extend his life. Such a decision must rest with the patient.
- But: the law assumes a constructive consent to such treatment as will save his life.
- The physician's dilemma is further complicated where the patient's immediate illness is not incurable but where a cure will leave him a permanent sufferer.

“Born” in 1969, Living Wills’ limited purpose and format remained unchanged—until now

- The suggested solution is that the individual, while fully in control of his faculties and his ability to express himself, indicate to what extent he would consent to treatment. The document indicating such consent may be referred to as “a living will.”
- If the individual's bodily state becomes completely vegetative and it is certain that he cannot regain his mental and physical capacities, medical treatment shall cease.
- A doctor cannot be directed to act affirmatively to terminate a patient's life. He may, however, be directed and exculpated to act passively by inaction.

Kutner, Luis. Due Process of Euthanasia: The Living Will, A Proposal. Indiana Law J. 1969;44(4):539-54. https://www.repository.law.indiana.edu/ilj/vol44/iss4/2/

No change in Living Wills' purpose or format—until now

Format: "If I reach *THIS* condition, then I want *ONLY THESE* interventions, which is **Counter-Factual Conditional**

Purpose: To give my advance informed refusal/consent to my future treating physician, which requires an adequate **appreciation** of the available specific treatments

Stop “Counter-Factual Conditional.” Ask instead: “How much suffering do you **judge** each condition would cause you & others you care about?” Revolutionary?

For 56 years, living wills’ **format** has been:

“If I reach *THIS* condition, then I want *ONLY THESE* interventions.” I now propose instead:

“I JUDGE this condition would cause me and those I care about *THIS INTENSITY* of suffering.”

The Revolutionary Change from “Counter-Factual Conditional” set of statements to “Judging How Much Suffering Each Condition Would Cause leads to expanding the **purpose** of living wills:

The **purpose** to complete living wills can expand **from:**

just **clearly expressing** what treatments capacitated articulate planning principals want in the future, **to:**

directly creating another document that can effectively implement the preferred treatment: a “Future POLST”

A Revolutionary Change: From "Counter-Factual Conditional" to "How Much Would Each Condition Cause You and Others to Suffer?“

The task of completing living wills changes **from**

“**If I** reach *THIS* condition, **then** I want *ONLY THESE* interventions” **to**

“I **judge** this condition would cause me and those I care about *THIS INTENSITY* of suffering.” ➔ SACP protocol ➔

The **Natural Dying Living Will** is comprehensive since it includes all **three types** of suffering:

1. Sensation-based
2. Functional-based*
3. Values-based
Notes: (A) There is some overlap
(B) Suffering from one type could cause suffering of another
***Original authors used the term “Flourishing-based”**

The **Natural Dying Living Will** is comprehensive
since it includes all **five sources** of suffering:

1. Physical/somatic (including non-observable pain)
2. Psychic/emotional (which can be as severe as #1)
3. Existential (including “deaths” of important relationships)
4. Disruption of life narrative (including tarnished memories)
5. Causing loved ones’ suffering (four ways above plus financial plus “ambiguous grief” and “bi-directional empathic suffering)

Old Agenda old items could be added

- Is your personal goal to experience a peaceful and timely dying and to minimize the burdens your disease imposes on others?
- How many Americans are now, and will be affected by dementia—a cruel, long, and burdensome disease (and similar terminal illnesses)?
- Why two factors make advance care planning (ACP) for advanced dementia so **challenging**?
- Why are moral **strategies** so important to fulfill one’s end-of-life wishes?
- What changes from traditional living wills and from new “dementia-specific” living wills are now recommended?
- What the basics of two options that are “treatments of last resort”?
- Do patients who have already reached advanced dementia, but lack an effective living will, have any effective options?

Agenda (can delete)

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Part Two:

1. My Way Cards: an easy-to-understand “patient decision aid” to appreciate what living with advanced dementia can be like for both patients and their family members

2. Three other strategic documents support or actualize your Natural Dying Living Will

3. Long after the planning phase, how will the phase of implementation begin?

A husband’s/widow’s perspective

- 1. Is she really suffering?
- 2. Would her past capacitated self want to continue life-sustaining treatment if it could prolong and increase her suffering?
- 3. Why is this type of grief called “Ambiguous”?
- 4. Why was it so surprisingly intense?

How to reduce this type of grief

1. Anticipate and educate
2. Appreciate that much suffering cannot be observed
3. Expand the concept of suffering to include inner feelings, future left memories, current burdens on loved ones, etc.
4. Keep firmly in mind: what would the patient want?

Natural Dying Living Will is comprehensive:
One way is that it includes **three types** of suffering:

1. **Sensation-based**
2. **Functional-based** (originally “Flourishing-based,” which is too-lofty)
3. **Values-based**

Note: Although there can be overlap, and suffering from one type could cause suffering from another, in my opinion, the concept is still useful (but see Nelson et al.’s work in progress)

Natural Dying Living Will is comprehensive:

Another way is that it includes **five sources** of suffering:

1. Physical/somatic (including non-observable pain)

2. Psychic/emotional (which can be as severe as physical)

3. Existential (including the “deaths” of important relationships)

4. Disruption of life narrative now and tarnished memories in the future

5. Causing loved ones’ to suffering the above four ways plus financial, “ambiguous grief,” and “bi-directional empathic suffering.

See the Table from my article ➔

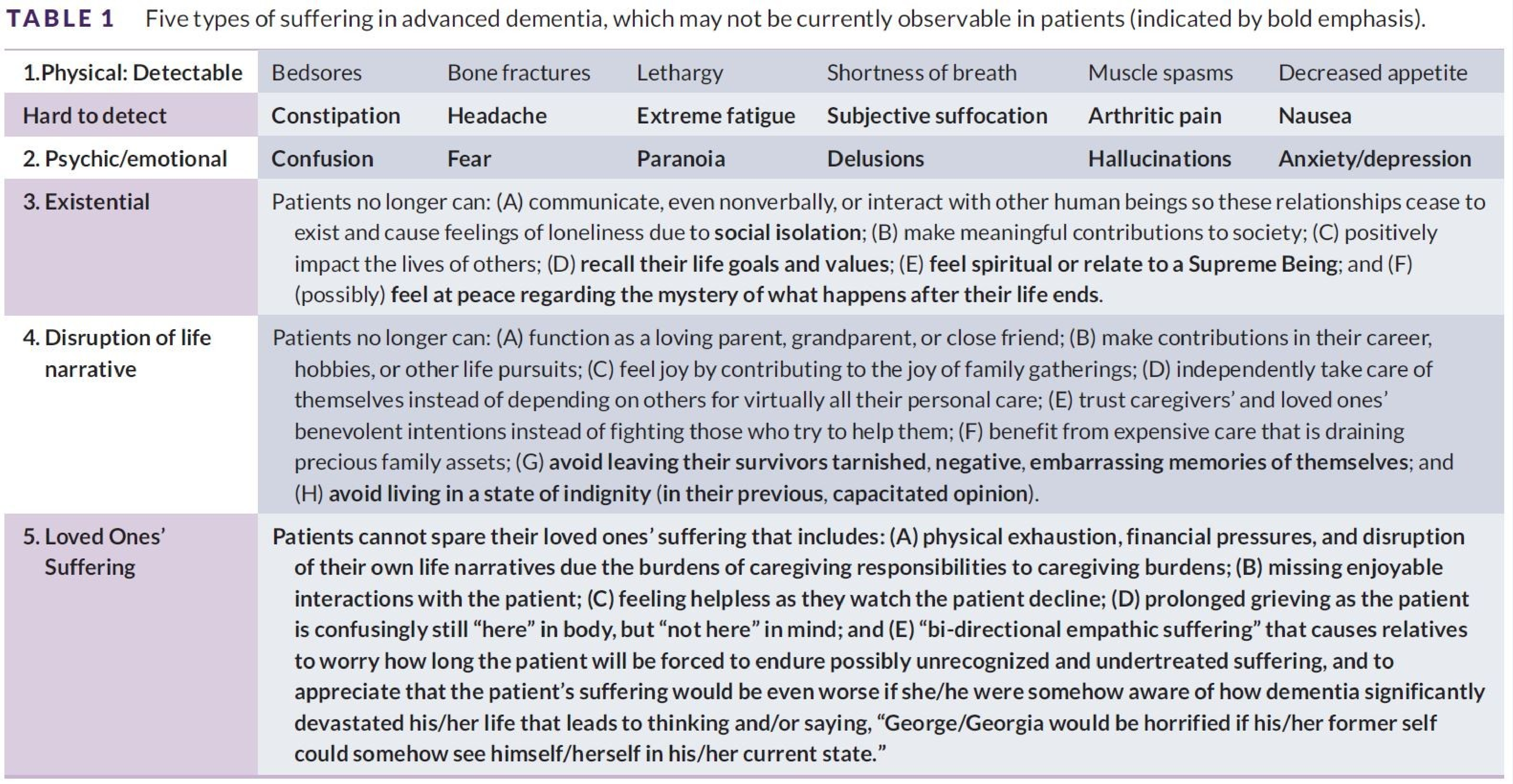

TABLE 1 Five types of suffering in advanced dementia, which may not be currently observable in patients (indicated by bold emphasis).

1.Physical: Detectable	Bedsores	Bone fractures	Lethargy	Shortness of breath	Muscle spasms	Decreased appetite
Hard to detect	**Constipation**	**Headache**	**Extreme fatigue**	**Subjective suffocation**	**Arthritic pain**	**Nausea**
2. Psychic/emotional	**Confusion**	**Fear**	**Paranoia**	**Delusions**	**Hallucinations**	**Anxiety/depression**
3. Existential	Patients no longer can: (A) communicate, even nonverbally, or interact with other human beings so these relationships cease to exist and cause feelings of loneliness due to **social isolation**; (B) make meaningful contributions to society; (C) positively impact the lives of others; (D) **recall their life goals and values**; (E) **feel spiritual or relate to a Supreme Being**; and (F) (possibly) **feel at peace regarding the mystery of what happens after their life ends.**					
4. Disruption of life narrative	Patients no longer can: (A) function as a loving parent, grandparent, or close friend; (B) make contributions in their career, hobbies, or other life pursuits; (C) feel joy by contributing to the joy of family gatherings; (D) independently take care of themselves instead of depending on others for virtually all their personal care; (E) trust caregivers' and loved ones' benevolent intentions instead of fighting those who try to help them; (F) benefit from expensive care that is draining precious family assets; (G) **avoid leaving their survivors tarnished**, **negative**, **embarrassing memories of themselves**; and (H) **avoid living in a state of indignity (in their previous, capacitated opinion)**.					
5. Loved Ones' Suffering	**Patients cannot spare their loved ones' suffering that includes: (A) physical exhaustion, financial pressures, and disruption of their own life narratives due the burdens of caregiving responsibilities to caregiving burdens; (B) missing enjoyable interactions with the patient; (C) feeling helpless as they watch the patient decline; (D) prolonged grieving as the patient is confusingly still "here" in body, but "not here" in mind; and (E) "bi-directional empathic suffering" that causes relatives to worry how long the patient will be forced to endure possibly unrecognized and undertreated suffering, and to appreciate that the patient's suffering would be even worse if she/he were somehow aware of how dementia significantly devastated his/her life that leads to thinking and/or saying, "George/Georgia would be horrified if his/her former self could somehow see himself/herself in his/her current state."**					

How to evaluate ACP:

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

(Others use data they can obtain now as a proxy: entries in electronic medical records indicated patient had the opportunity to discuss end-of-life goals and to choose what options they prefer to attain them. (E.g., the intense ongoing research of the “JumpStart” protocol.)

Two decades of continual improvement

Valuable input from clinicians, attorneys, psychologists, chaplains, patients, family members—both during the process of ACP and LATER. If you GET what you WANT, then ACP was SUCCESSFUL: *Physicians/providers will promptly assess their patient's clinical condition upon request or observing a change in their condition, and if the patient meets the qualifying clinical conditions described in the living will, they will promptly comply by implementing the corresponding preferred treatment. This defines **SUCCESS.***

Example of dual function: I now use **AI** to facilitate patients’ final, collaborative **Deliberate Capstone Review**, which lets them leave a final message for their family (and provides me with feedback).

- The challenges of advance care planning (ACP) for advanced dementia
- Why success depend on moral strategies (even if you have no personal moral conflict)
- Defining two **“**treatments of last resort”: both are controversial
- “Discovering” a large subgroup of previously neglected patients
- “My Way Cards” = the patient decision aid; “DDDD” = the goal of the protocol: demonstrate diligence and deliberation as you make end-of-life decisions
- An alternative protocol can help patients now living in advanced dementia without an effective living will
- Unexpectantly profound grief: can physicians reduce it proactively? (Video excerpt of an interview with a widower)

Why do estimates change over time?

Ability to diagnose dementia at onset and as the cause of death are improving --> Increase in actual future estimates

Lifestyle changes and other factors --> Real decrease future estimates

<table>
<tr><th>The Intensity of Suffering That You Judge . . . For a Condition ➔</th><th>Which Treatment (POLST) is in Your “Natural Dying Living Will”</th></tr>
<tr><td colspan="2">**This part of the protocol has three ADVANTAGES**</td></tr>
<tr><td colspan="2">1. It may prevent planning principals from choosing the same treatment for every condition (regardless of how little suffering).
2. It focuses on the most compelling reason to allow a patient to die—severe suffering.
3. It uses the most effective form available: POLST orders are **immediately actionable**; **must be followed** by other providers; and **apply in all treatment settings**. POLSTs actualizes the planning principals’ judgments for which the moral response is to reduce suffering.</td></tr>
</table>