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

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

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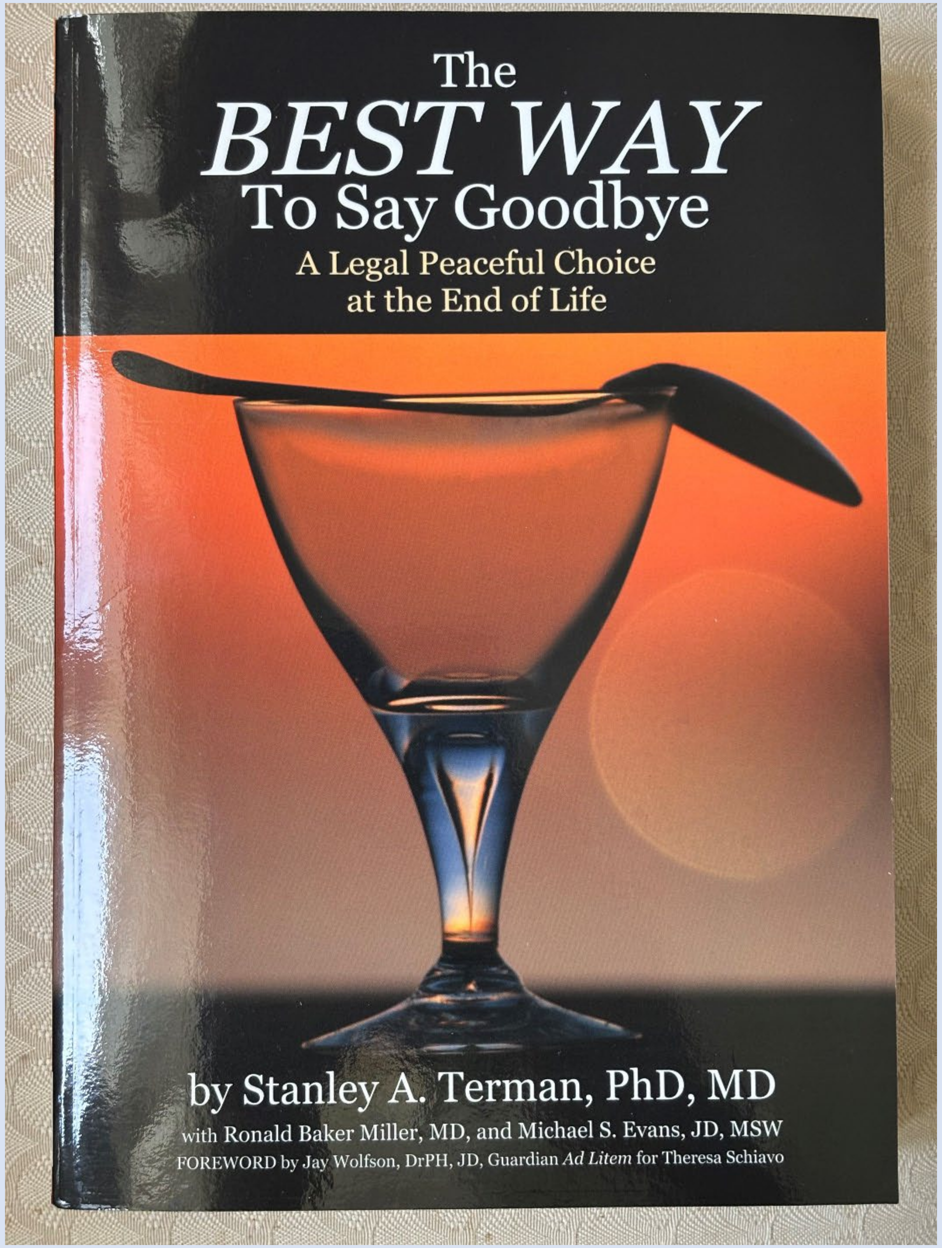
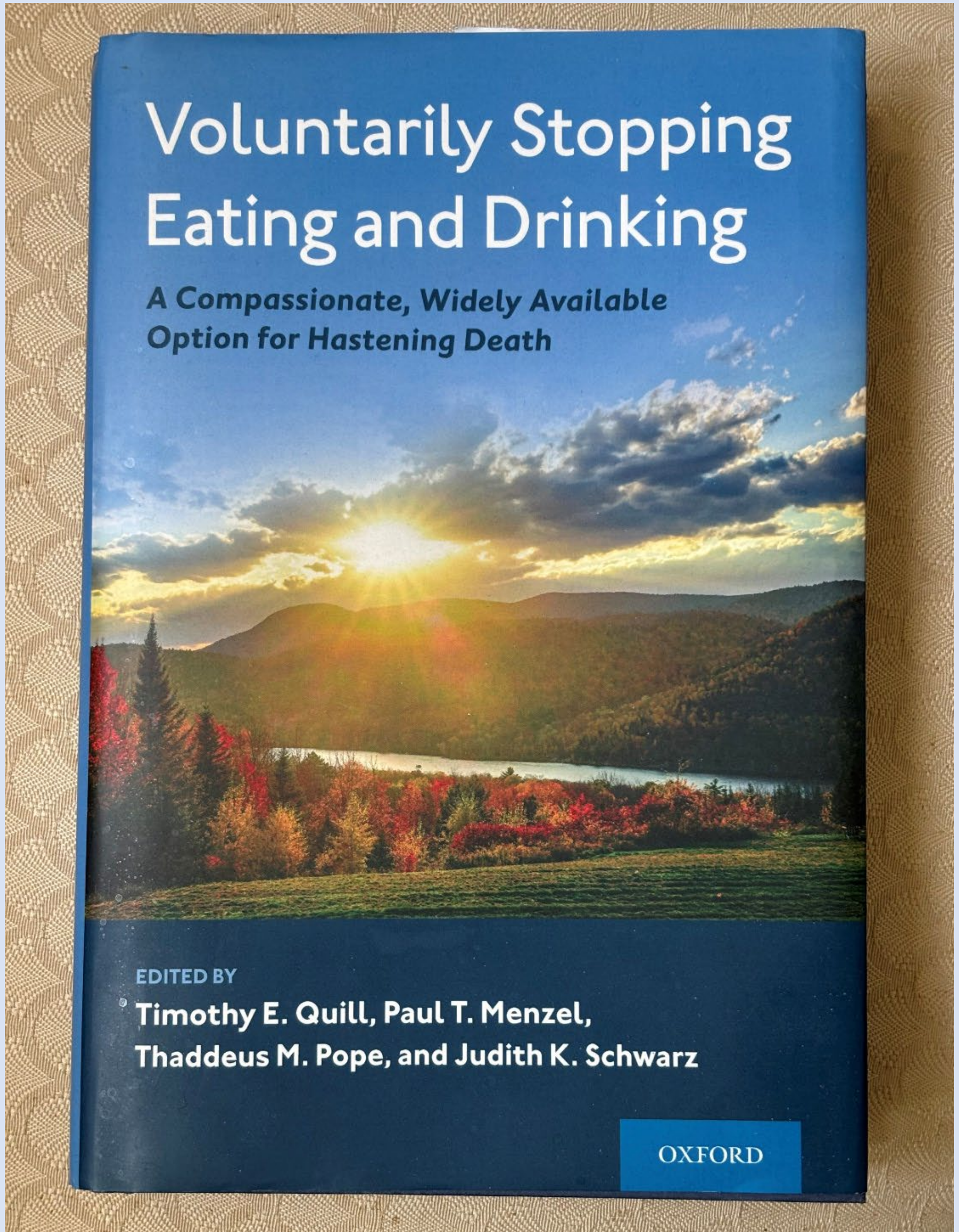
A tale of two books: 2007 and 2021



The
BEST WAY
To Say Goodbye
A Legal Peaceful Choice
at the End of Life

by Stanley A. Terman, PhD, MD
with Ronald Baker Miller, MD, and Michael S. Evans, JD, MSW
FOREWORD by Jay Wolfson, DrPH, JD, Guardian *Ad Litem* for Theresa Schiavo



Voluntarily Stopping
Eating and Drinking
A Compassionate, Widely Available
Option for Hastening Death

EDITED BY
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OXFORD

Today’s Agenda

- Understand advance care planning (ACP) challenges—for a peaceful and timely dying after reaching advanced dementia
- Appreciate a large subgroup of patients who until now, have been largely neglected as presenting distinct challenges
- Patient decision aids and ACP protocols must strive to be moral so those in authority will accept them
- Two treatments of last resort: “Natural Dying,” and “Moderate Anesthesia.
- The “DDDD” protocol demonstrates diligence, and deliberation in decision-making. An alternative protocol if no effective living will.

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. **EXAMPLE of a "READ-LATER" SLIDE.**

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

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

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

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

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

Why morality matters in end-of-life care

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

Advance care planning (**ACP**) cannot be successful unless the prescribing physician/provider and institution agree to implement the orders patients need, which requires their acceptance, which often requires them to view the living will and protocol as moral.

If ACP fails, prolonged dying with suffering can result.

To Still be Moral, focus on INTENT

- Documents and clinicians' behavior should be consistent with the INTENT was **not to hasten patient's dying**

- Instead, they must support the INTENT was **solely to relieve patient's suffering**

- Applies to both the advance care planning (ACP) phase and (hopefully, much later) the implementation phase

Double Effect: A 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.

Why is it so hard to attain a timely, peaceful dying with dignity?

Patients living with dementia will lose their ability to make treatment decisions (decision-making capacity, **DMC**) years before they die, so they **cannot**:

- Speak for themselves just when it's most important
- State what treatment they do or do not want now
- Revise their living wills to make them currently effective

Other Similar Terminal Illnesses include:

- Cerebrovascular accidents (stokes)
- Persistent vegetative state
- End-stage renal disease
- End-stage liver disease
- Heart failure if severe
- Advanced cancer patients receiving high doses of opioids for pain

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

The elusive holy grail of living wills

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

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

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

The goal for living wills:

Want = Get

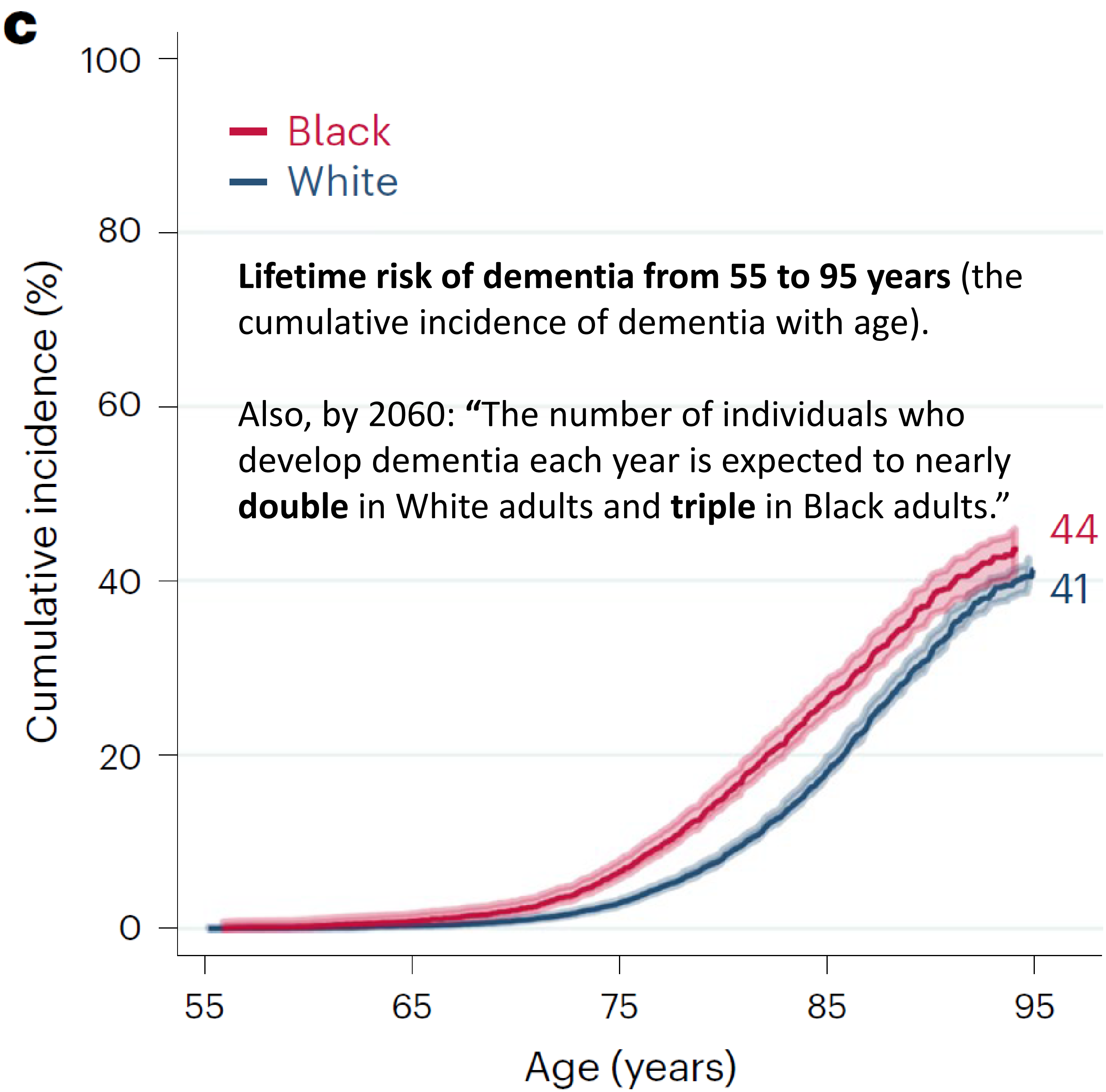
Unfortunately, without effective strategies:

Want ≠ Get

A glimpse at the extent of the problem:

- About 6 million Americans have dementia
- About 2 million (11% of those of 65) Americans live in advanced dementia
- One-third of people over 65 die with dementia
- “**The lifetime risk** of dementia after age 55 years was **42%** [but…] substantially higher in women, Black adults and APOE ε4 carriers” (up to 60%).*

*Fang M, Hu J, Weiss J, et al. Lifetime risk and projected burden of dementia. Nat Med. 2025 Jan 13. doi: 10.1038/s41591-024-03340-9



Lifetime risk of dementia from 55 to 95 years (the cumulative incidence of dementia with age).

Also, by 2060: “The number of individuals who develop dementia each year is expected to nearly **double** in White adults and **triple** in Black adults.”

My estimates:

- Between 1.5 and 2 million Americans lack “effective” living wills whose instructions can relieve suffering in the late or advanced or severe stage of Alzheimer’s and related dementias and similar terminal illnesses
- At least a half-million Americans are living in the Dementia Gap (will define this soon)

(These calculations are presented in appendices in two articles that will soon be submitted.)

Comments on why these estimates change:

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

Lifestyle changes and other factors --> decrease future estimates

Why is advanced dementia so challenging?

Advanced dementia has limited end-of-life options—if suffering becomes enough to want to be allowed to die

The FIRST challenge is "No Plug to Pull": patient is not dependent on high-tech treatment to live

Traditional living wills that are silent regarding food and fluid:

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

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

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

Feeding can arguably be judged as
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

A second, newly identified **limitation**

Patients can still feed themselves (eat and drink independently)

—in addition to having "no plug to pull,“ and incapacity.

Unusual: a retained Activity of Daily Life is a liability → limitation.
May not be fun for patient or “dignified”

How? The progression of mental dementia causes the loss of mental functioning faster than physical capacities.

Withholding food &fluid is **illegal** euthanasia; **not** an option.

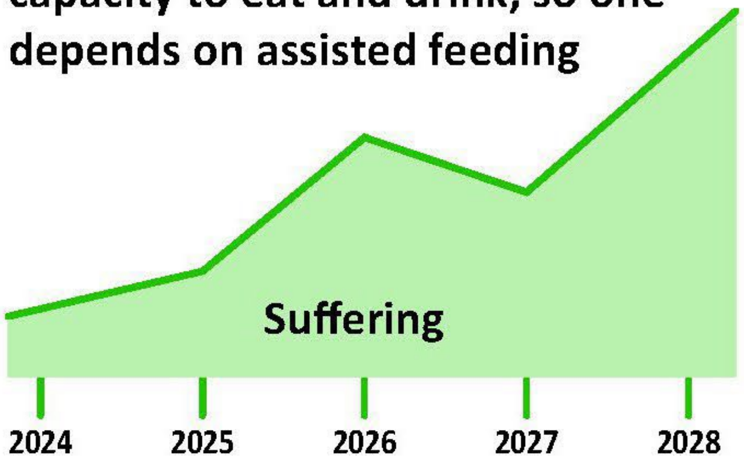
Patients who live in the **Dementia Gap**

A previously unidentified substage of dementia, in which patients:

- Lack capacity
- Do not depend on assisted feeding
- Some want treatment to relieve their exceedingly severe suffering despite the possible risks of treatment

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

Three “two’s”—a clarifying slide (I hope):

➔Two stages/substages: those who live in the Dementia Gap; the rest depend on assisted feeding.

➔ Two kinds of treatments of last resort: Natural Dying and Moderate Anesthesia.

➔ Two types of planning: those who completed a living will and those who did not—who depend on their agents’ substituted judgments.

Are “Dementia-Specific” Living Wills Effective?

In 2022, *BioMed Central Medical Ethics* published our critical review of new dementia-specific living wills. All had one or more of 24 identified flaws that could lead to premature or prolonged dying.

Types of flaws: process, content, inherent, and absence of 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.

Example one: a living will stated its intended audience was patients with early dementia, but it required reading comprehension of **grade 14** (college sophomore).

Example two: no living will included 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 not adequate; legal action is required.

The Natural Dying Living Will:

- In continual development since 2006
- Uses the patient decision aid, **My Way Cards**
- Illustrated since 2009 by collaborating with William Young
- Comprehensible at reading level of grade **3**
- Content validity improved confidence = all interpret words and drawings the same, as designed
- Free “Demo” for experiencing the online program
- Why **My Way Cards** are **not** for sale separately

Valuable input from clinicians, attorneys, psychologists, chaplains, patients, family members—both during the process of ACP and LATER. (Recall: you GET what you WANT = “SUCCESS”:

*Physicians/providers will promptly assess their patient's clinical condition upon request or observing a change in 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, which is typically expressed by statements in the format, "**If** I reach these specific medical conditions, **then** I want only these particular treatments: . . ."*

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

Caring Advocates’ **Natural Dying Living Will** offers two treatments of last resort

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

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

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.

The second treatment of last resort

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

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 you now want to resume conscious living?"

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

Expanding the theme of reducing suffering by offering both Natural Dying and Moderate Anesthesia

Terman SA. Can an effective end-of-life intervention for advanced dementia be viewed as **moral**? Alzheimers Dement (Amst) 2024;16(1). DOI: 10.1002/dad2.12528 (See also, our response to the Alz. Assoc.'s rebuttal article.)

*Terman SA. Relieving Refractory Suffering in Advanced Dementia with Two Protocols—one for Advance Care Planning and one for Patients Who Reached Late-Stage Dementia Lacking an Effective, Legal, and **Moral** Directive.

(*Work in progress)

It’s easy to use **My Way Cards**

The task of **planning principals** (or of agents/surrogate decision-makers) is to **judge how much suffering each condition** (as described and illustrated in a My Way Card) **would cause.**

These judgments are based on **patient's lifelong values and treatment preferences**. Some planning principals need counseling about these areas—if new to then.

Agents/surrogates use "**substituted judgment**" by using their functioning mind and their knowledge of the patient's values and preferences—as they attempt to make the **same decision** the patient would have made about each condition—if asked before losing DMC.

Decision-makers choose 1 of 4 levels of suffering:

No or mild suffering

Tolerable suffering

Severe suffering

Exceedingly severe suffering

Each corresponds to a different level of POLST care

Four "Suffering-POLST" Levels of Care Connection:

CPRL = one last cardiopulmonary attempt for conditions that cause **mild or no suffering**. (SLT + 1 CPR)

Selective/Limited Treatment (**SLT**) = for conditions that cause **tolerable suffering** (no invasive/burdensome Tx)

Natural Dying (**ND**) = for conditions causing **severe suffering**, Comfort-focused care and medical dehydration

Moderate Anesthesia (**MA**) = if **suffering** is **exceedingly severe**, sedation makes patients unaware of—dissociated from—their suffering

Purposes of illustrations:

- Clarify condition, make it easier to understand, help improve content validity
- Add specific clinical detail for some conditions
- Depict typical emotional responses of patients and family
- Can resonate with planning principals' emotions
- Common ground if future translations used

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

(P = Published; S = Submitted to journals)

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.

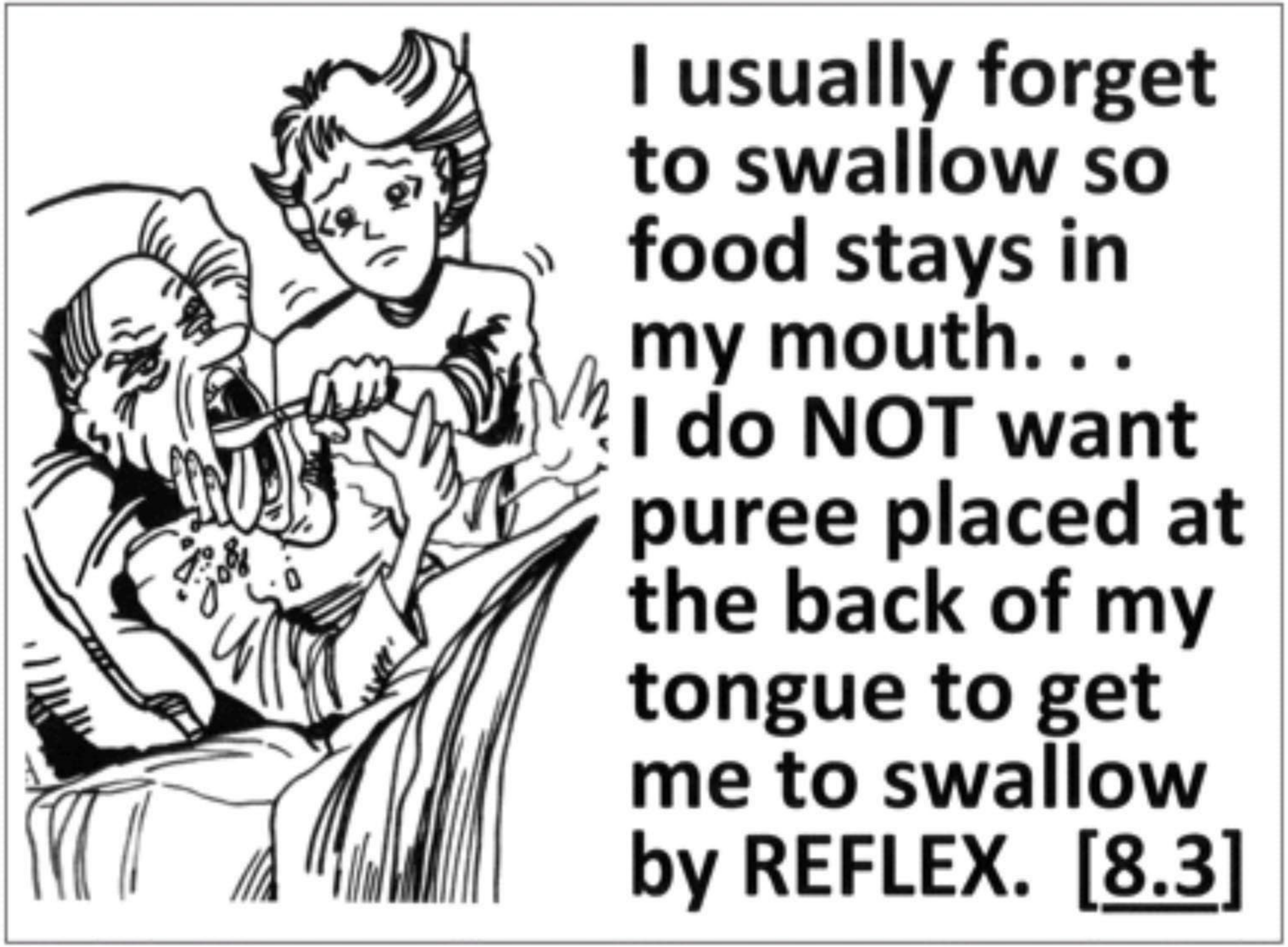
P

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]

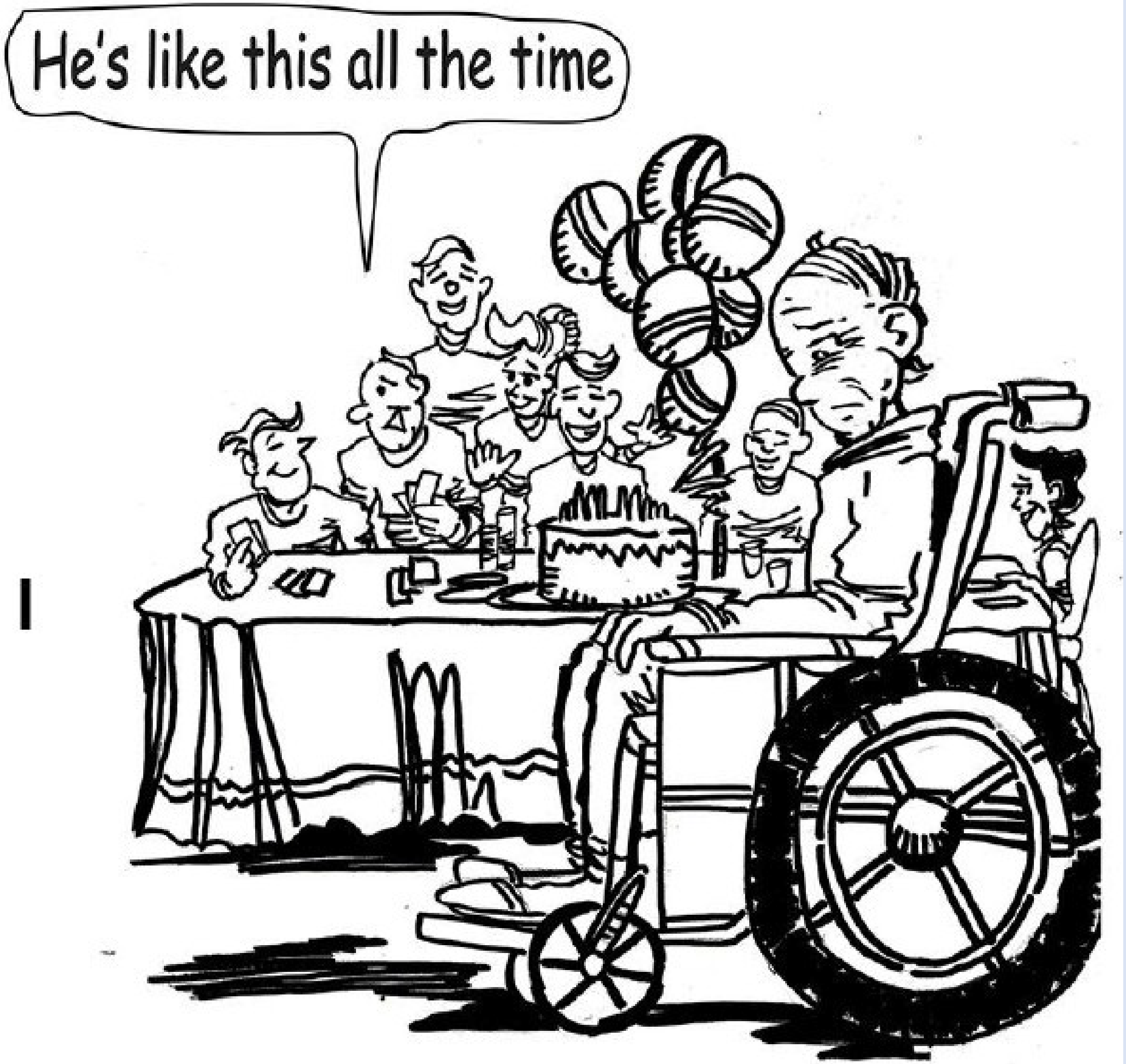
P

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]

SUCCESS in ADVANCE CARE PLANNING:

Your future treating physician/provider promptly implements the instructions for treatment that you previously had expressed—without conflict.*
*NOT: entry into an EHR that discussion occurred permitting decisions in certain area (JumpStart protocol, that is the subject of intense research).

This requires additional effort in ACP □

Strategic Advance Care Planning's **DDDD**:

- 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 they're 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 four documents of Strategic Advance Care Planning—record on video & notarize:

1. Natural Dying Living Will
2. Bilateral durable power of attorney for healthcare decisions
3. Natural Dying Agreement
4. “Future POLSTs” (up to ten)

The “Dear Doctor” strategy (in the NDLW):

- 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.

Bilateral durable power of attorney:

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.

Natural Dying Agreement—Table of Contents

Two protocols for two types of patients

Strategic Advance Care Planning is for people who have capacity.

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

NOW Care Planning is for patients who lack capacity and already reached an advanced stage of dementia, but did not complete an effective living will.

Advantages: only some strategies are available, but they may suffice.
To my knowledge, it is the best legal, ethical, and moral approach available.

Two protocols ask slightly different questions:

For **Strategic Advance Care Planning**, the repeating question is:
“How much suffering do *you* judge this condition would cause you or your family members?” (Always present all 50 conditions.)

For **NOW Care Planning**, the repeating question is:
“How much suffering would < patient> have judged this condition would cause him/her and family members —if asked before losing capacity?”
(To complete this task, they use their substituted judgment (as explained) and their extensive knowledge of <patient>.)
(Can present a selection of about 20 conditions.)

To identify conditions the patient would judge as causing exceedingly severe suffering: PDC members cast their votes

Each decision-maker was asked to use their substituted judgment to opine:
“If the capacitated AK of the past had been asked, would she have judged any of these conditions are NOW causing exceedingly severe suffering—which qualifies her for Moderate Anesthesia?

Summary (Conditions’ exact wordings are listed below)	Husband/ agent	Caregiver	PDC 1*	PDC 2*	PDC 3*	Treating Physician
1.5 Lacks social judgment	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
2.1 Cannot use words meaningfully	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
2.2 Cannot indicate Yes or No	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
3.2 *Existential suffering**	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
4.4 Fights caregivers	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
4.6 Embarrassing actions	**Y**					
5.2 Cannot socialize/enjoy family	**Y**					
5.3 Agitation		**Y**				
5.6 Angry, hits people	**Y**	**Y**				
6.3 Treatment is futile						**Y**
7.6 Mind/body paradox harms others		**Y**				**Y**

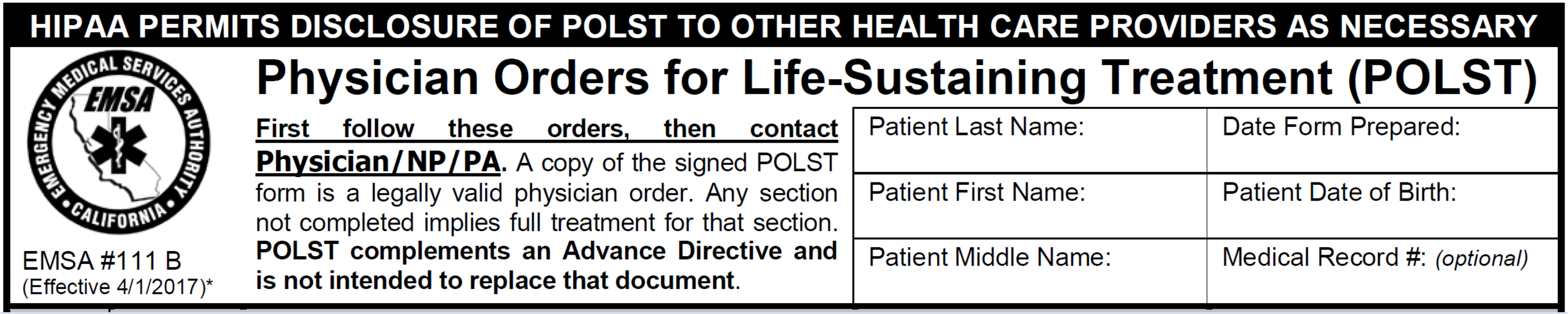
Why “Future POLSTs” can be effective

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

Additional (unique) Strategies:

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

Why “Future POLSTs” can be effective



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

Physician Orders for Life-Sustaining Treatment (POLST)

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)*

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

As clear as possible:
First follow these orders, then contact Physician /NP/PA.

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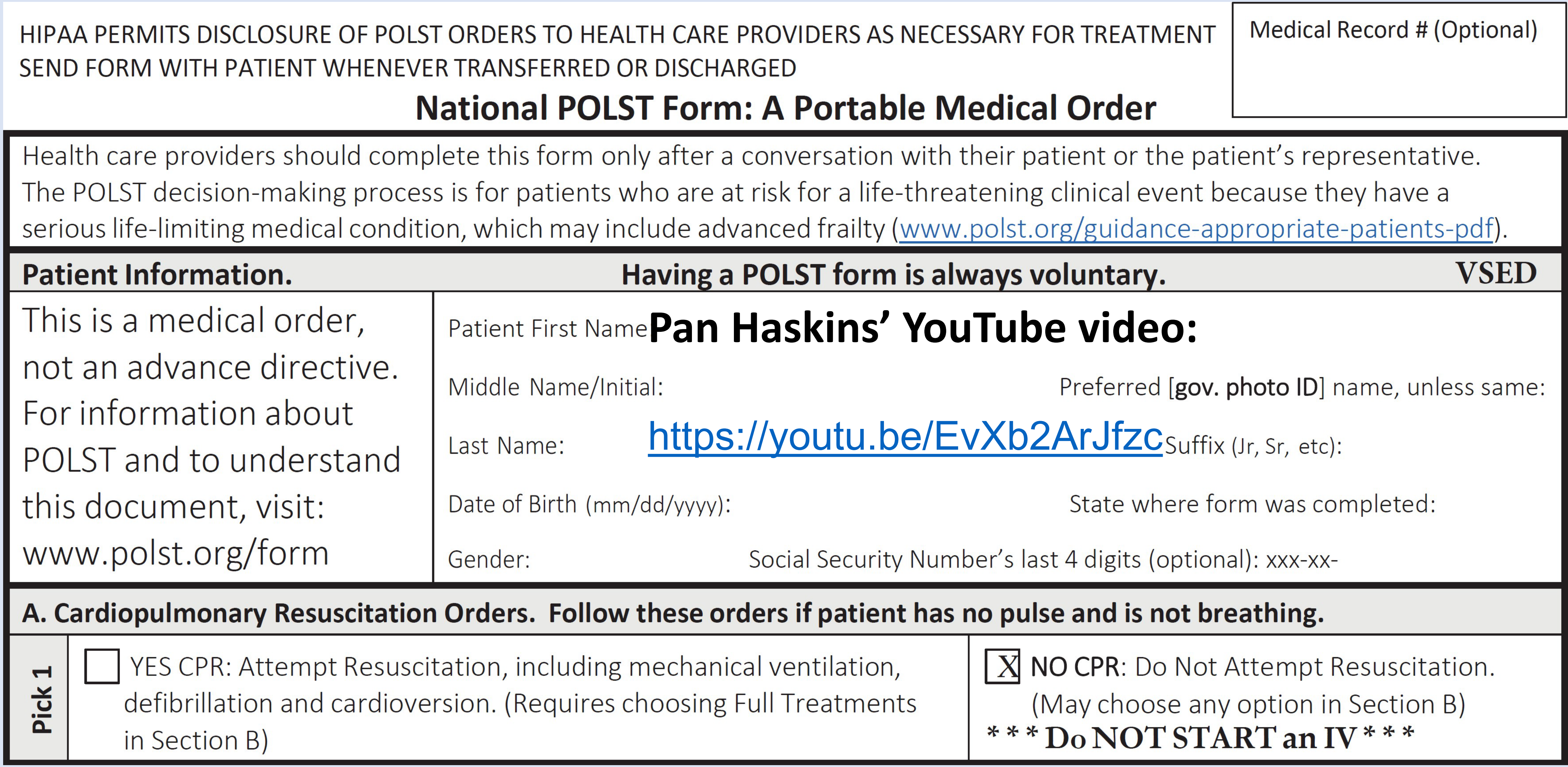
Why “Future POLSTs” can be effective

Linking a living will with a POLST can transform

what some physicians/providers might consider a “request—if you agree, dear doctor, please”—to the strategic authority of a physician order.

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

- Used as medical/legal “insurance” to prevent others who would—perhaps in good faith, but incorrectly—attempt to sabotage your end-of-life plan
- VSED cannot be chosen unless you still have capacity
- This POLST is an example of one of TEN Future POLSTs
- Your Patient Decision Committee votes on which one is now clinically appropriate—OR you decide if you still have capacity



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-

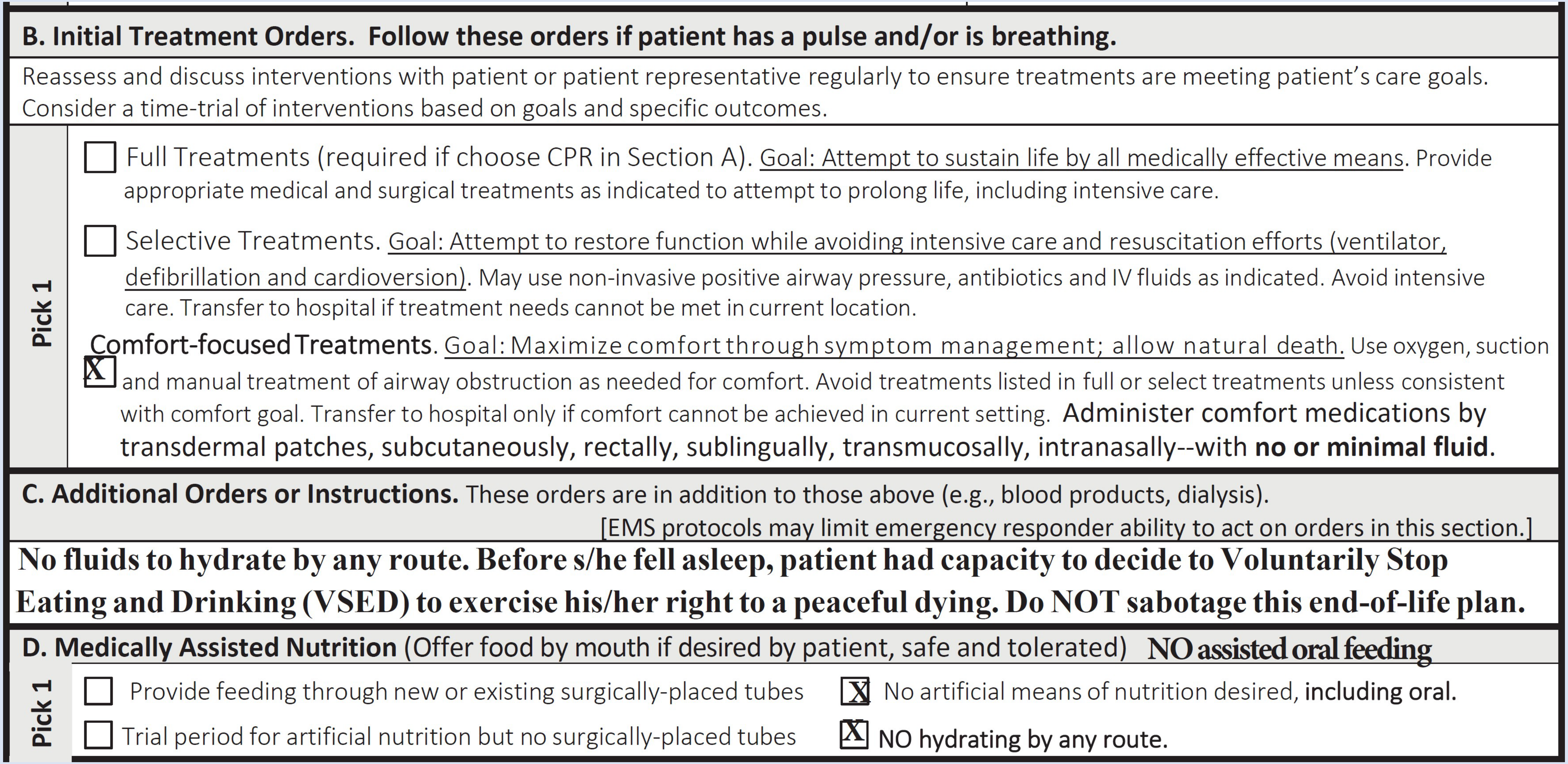
A. Cardiopulmonary Resuscitation Orders. Follow these orders if patient has no pulse and is not breathing.

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 * * ***



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

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

Pick 1

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

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

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

C. Additional Orders or Instructions.

These orders are in addition to those above (e.g., blood products, dialysis).

[EMS protocols may limit emergency responder ability to act on orders in this section.]

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

D. Medically Assisted Nutrition

(Offer food by mouth if desired by patient, safe and tolerated) **NO assisted oral feeding**

Pick 1

☐ Provide feeding through new or existing surgically-placed tubes

☐ Trial period for artificial nutrition but no surgically-placed tubes

☒ No artificial means of nutrition desired, **including oral.**

☒ NO hydrating by any route.

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

Final Points:

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 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 many symptoms that are inherently untreatable. See Sarah's story.

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 our dying if only to prevent “getting stuck” in an advanced stage of dementia. There are alternatives.
- One alternative is “Strategic Advance Care Planning.”
- So, your call to action: if you still have capacity: be proactive.

- **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 often needed strategies, learn more about **NOW Caring Planning**.

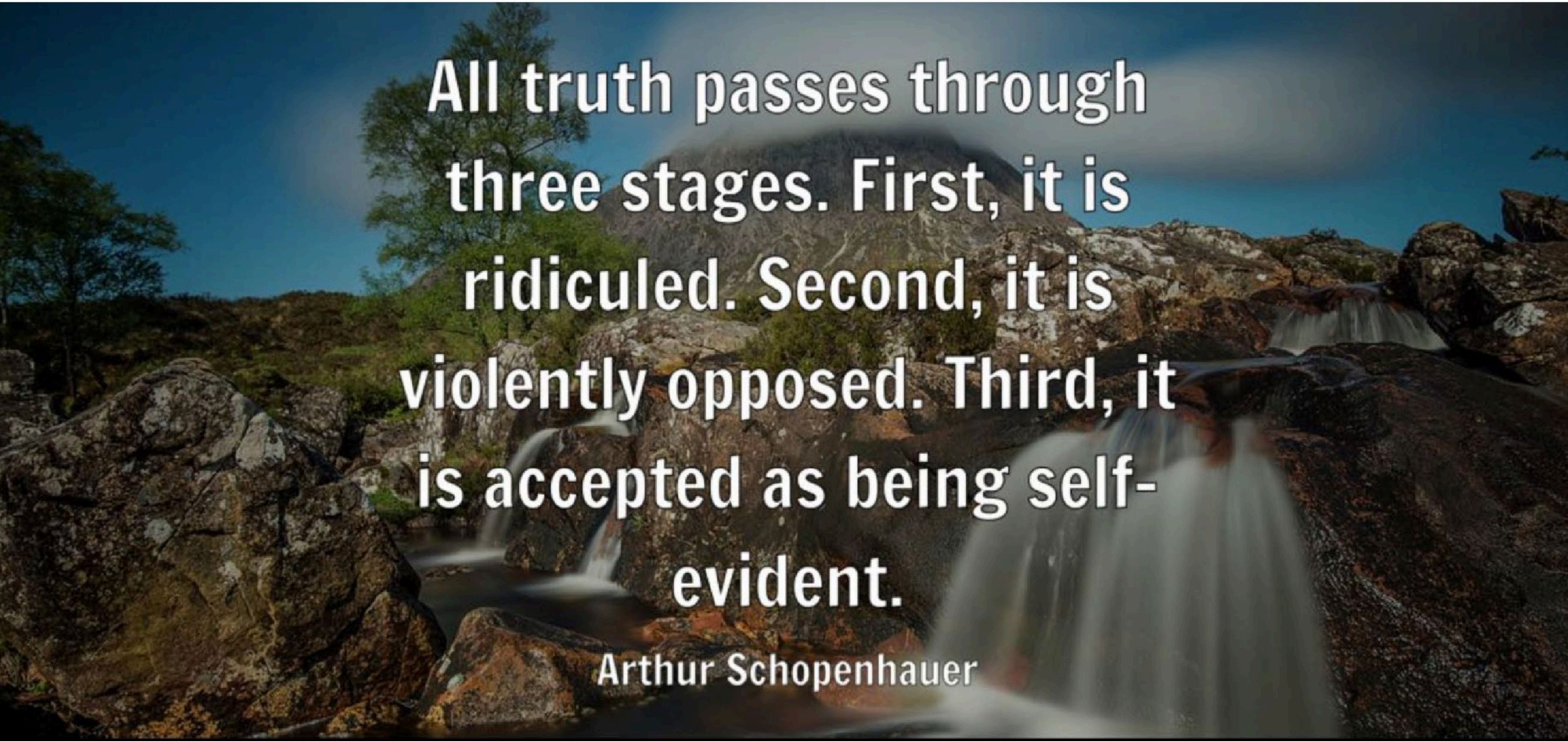
Strategic Advance Care Planning

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

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

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- More information: CaringAdvocates.org website
- New files are at CaringAdvocates.org/newstuff/
- A video should be available soon.