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

Yes—If Your Strategies are Clinically Appropriate, Legal, Ethical, and Moral

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Hosted by: **Funeral Consumer Society of Colorado**

Optional: Take our 10-item survey, so we can understand your values and what you want.

- The Question: Did attending the presentation change any of your views?
- Takes about 5 minutes.
- You can leave Zoom and come back or have both windows open. Last resort: use pen and paper to write down your response to ten questions; take a photo; send to us. (You can hide your identity.)
- We will ask you to repeat the survey at the end. (It will take less time.)
- To match your responses, write a 4-digit number from your date of birth in this sequence: YYMM. If born in April 1955: code is 5504.
- If you decide to participate, we thank you.

1. The story of “Sarah”: A fictional composite patient whose treatment reflects common, real challenges and ineffective treatment. Example:
She was a victim of the dangerous, dismissive non-sequitur fallacy committed by casual observers. They extrapolated from her calm exterior (very withdrawn behavior) to wrongly assume that her mind was in a state of inner peace. She actually had Non-Observable Suffering (N-O-S).
Others were wrong in saying,
“She’s not suffering; she’s just sitting there.”

(*Please read these 2 pages before or after the presentation.*)

Sarah: **Beyond Suffering in Silence: The Agony of Non-Observable Suffering (N-O-S) 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 a 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 judging: “**She’s not suffering. She’s just sitting there.”** This **dangerous non-sequitur** fallacy equates outward calm—actually, pathological withdrawal—with inner peace. 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 the authentic wishes patients expressed before they lost capacity. It motivates investigating sources of suffering more vigorously, so the appropriate treatment to reduce suffering can be offered.

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. (Excerpt from Dr. Terman’s forthcoming article.)

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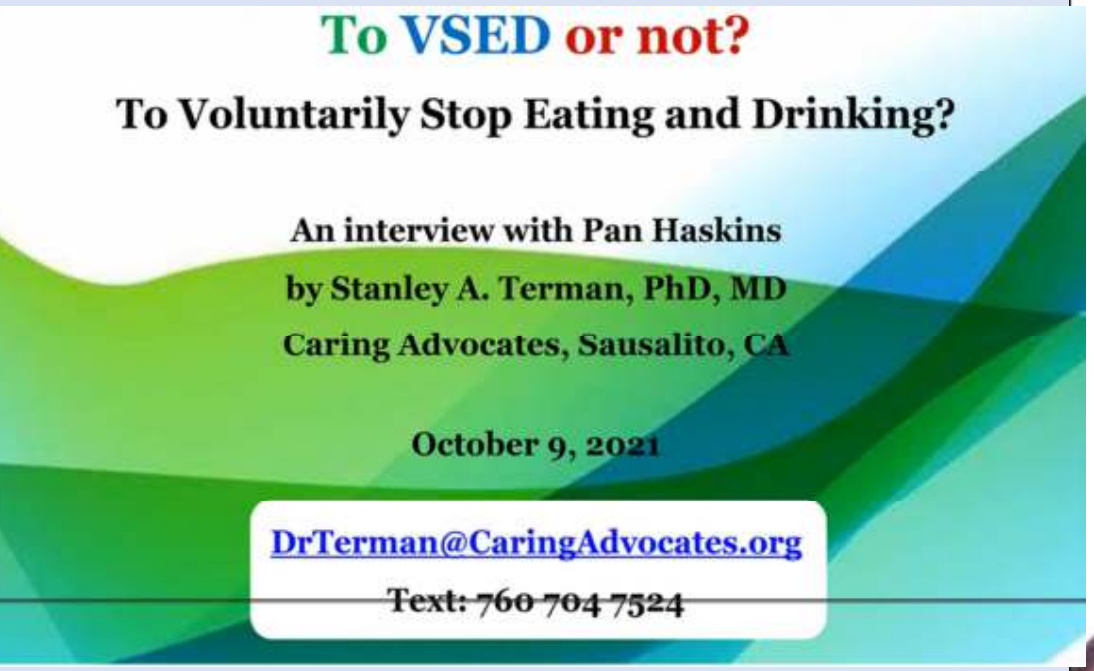


She made two videos. One was a 12 minutes; the other, just over an hour


Go away.

2. Pan Haskins received “medical-legal” insurance to ensure she would have a timely and peaceful dying. She did not qualify for Medical Aid in Dying. She felt that continuing life-sustaining treatment led to severe suffering that would only get worse. We recorded a video interview designed to convince viewers that her decision to Voluntarily Stopping Eating and Drinking (VSED) was right for her—based on her lifelong values and current condition. Her “VSED-POLST” carried the authority of physicians’ orders and included her consent.

POLST and MOST—why complete during advance care planning?

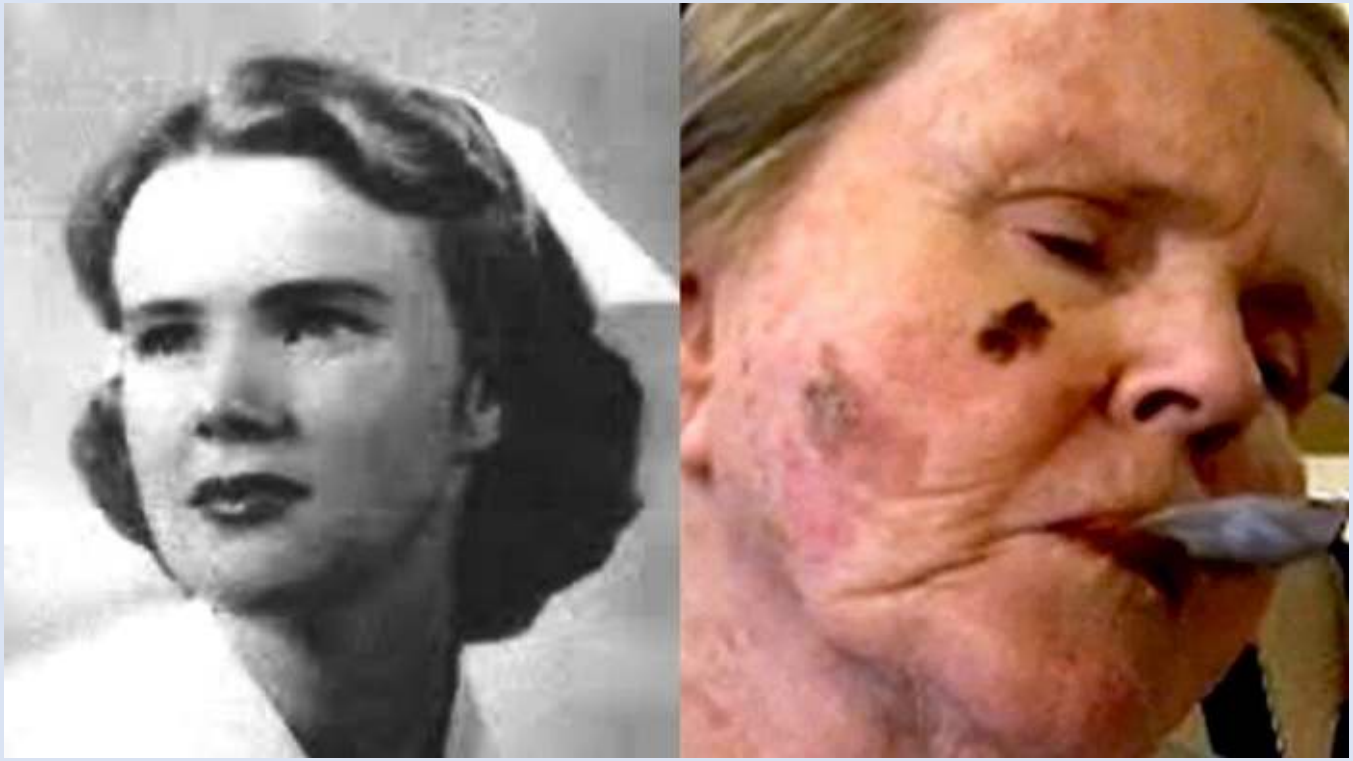
- Physicians'/Providers' Orders for Life-Sustaining Treatment (POLST)
- Medical Orders for Scope of Treatment (in Colorado, which accepts similar forms). (Used interchangeably in this presentation.)

- In Caring Advocates' **Strategic Advance Care Planning**, POLSTs are completed during advance care planning (ACP)—when the patient ("**planning principal**") still has a functioning mind to decide based on **lifelong values & treatment preferences**.
- This unique protocol leads to several "**Future POLSTs**." Completing these forms do **not** wait until the patient is terminally ill. So usually, surrogates must be asked to make life-determining decisions. Compared to the ideal of making the same decisions the patient would have made, Shalowitz et al. reported only **58% concordance** (agreement) for dementia—worse than 68% for all diseases
- ➔ If you want to successfully control the last chapter of your life, make these decisions yourself while you still can!

3. Margot Bentley was well-informed, well-motivated and exerted her best effort to create a living will designed to avoid prolonged suffering in advanced dementia. It asked to **“not be provided with ____ nourishment or liquids”** and to be allowed to die if she suffered from “extreme disability with no expectation of recovery.”

Unfortunately, Margot omitted the word “**oral.**” The result: almost 4 years of court-ordered force feeding while she could not absorb what doctors ordered caregivers to put in her mouth. **Warning**: the last photo—how she looked before she died—is hard to see. ➔

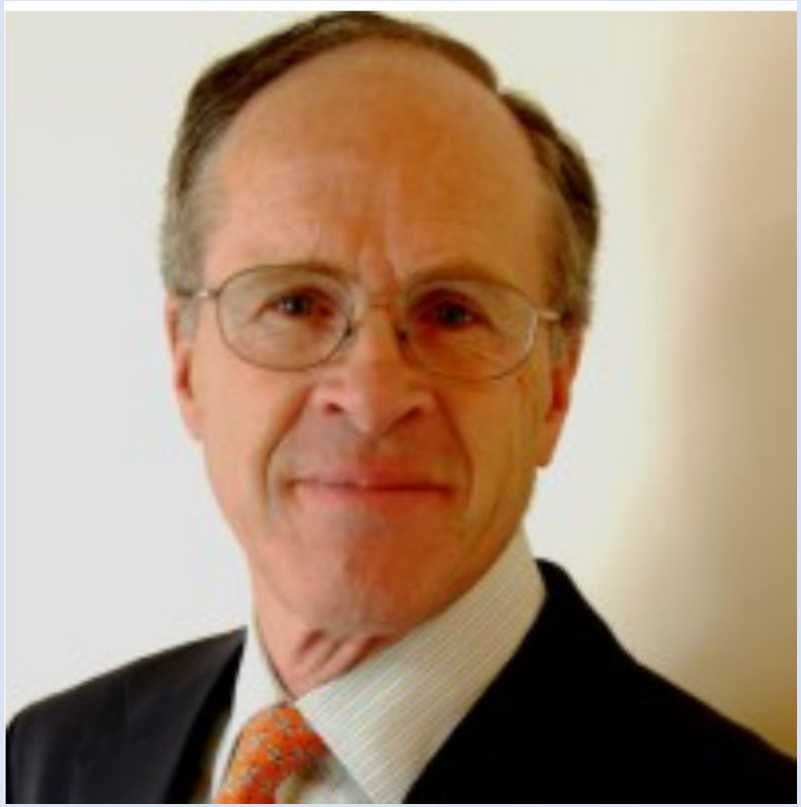
Margarette Bentley: a young nurse and plump, when spoon feeding in advanced dementia began



After almost 4 years of force feeding. (What a difference one word can make.)

4. My patient, “AK,” received the current ACP Caring Advocates protocol in 2019—but it could not work when her suffering became intolerable in 2023.
She needed two protocol enhancements:
(1) A **broadened concept of suffering** (which I was then working on and was published in 2024).
(2) A new, second treatment of last resort: **Moderate Anesthesia**, to make her unaware of her suffering (that can work for terminally ill patients if suffering cannot be relieved by non-sedating treatments). Her challenge: She could not use “VSED by AD” / “Natural Dying” because she retained the physical ability to eat and drink without assistance. She was living in the **Dementia Gap**.

"AK's" husband and I worked together intensely—before and after AK died.
Together, we discovered why his grief was so much more profoundly deep than either of us had expected:
Ambiguous loss.



- Next: the results of the members of her Patient Decision Committee: They reached an expression of consensus of substituted judgment.

Patient Decision Committee members vote: Does patient's current intensity of suffering 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—whether used for SACP or NCP—include:

No one person has to shoulder all the existential angst from making an awesome existential decision

Likely more accurate treatment decisions by multiple decision-makers that by one person (not yet proven)

May help prevent self-interest behaviors of one agent

Might discover social history and personal preferences to help withdrawn patients awaken to enjoy life

Emotional support both now and to reduce later grief

The “**Dementia Fear”** causes many patients to experience anxiety and worry. They wonder: “Will others honor my wishes after I no longer can speak for myself? Will my living will succeed in **preventing prolonged dying with suffering in late-stage dementia** or another terminal illness?”

The Dementia Fear can lead to suicide attempts and hastening dying by stopping life-preserving mediations. These actions may prematurely sacrifice many months to years of reasonably good quality living. Also, patients may be denied effective treatment in middle-stage dementia. Loving spouses can commit mercy killings in late-stage.

Plan Now, Die Later—to Live Longer

Planning principals can complete Strategic Advance Care Planning by diligent, deliberative, decision-making. They can determine what treatment they will, or will not, receive if they reach specific future conditions. Confidence that others will honor their end-of-life wishes, so they successfully attain what they consider goal-concordant care, can free them from anxiety, worry, and planning their own premature dying. They can enjoy living for as long as their suffering remains mild or tolerable.

The goal for living wills:

Want = Get

Without effective moral strategies:

Want ≠ Get

Nolo's living will now includes Voluntarily Stopping Eating and Drinking (VSED)

Some people who are close to death or suffering greatly want the option to **hasten death** by voluntarily stopping eating and drinking (VSED). . . Alzheimer's may **WANT their health care agents to enforce** this wish by instructing providers to stop feeding them.
<HOPE since agents lack authority to enforce; and "hasten" can be viewed as immoral .>

. . . VSED can lead to a natural, pain-free death. However, **many health care providers do NOT understand or accept it and MAY REFUSE these requests**. . . make sure to clearly write **. . .** :
<HOPE since this is NOT an effective strategy.>

"If I ever . . . **do not recognize my family** I believe that it would be **best for me to die**. **<Problems are wrong & immoral>** . . . If I feed myself, I live another day; if I do not, I will die and that is fine." (WA Hensel, My Living Will, 275 *JAMA* 588 (1996). **<HOPE provider is not strict on being moral.>**

You can give your health care agent the power to make sure this wish is carried out if you cannot speak for yourself. . . **some hospitals and states may not honor your wishes**. It is important to make your desires as clear as possible. **<HOPE since clarity is not likely to be effective—even if Nolo showed you precisely how to be clear.>**

From Hope to Confidence: From Least to Most Diligent, Comprehensive, and Likely Successful Advance Care Planning for Dementia	
Extent of Advance Care Planning	**Is Hope or Confidence Warranted?**
No ACP, lacks decision-making capacity, so the only option is “NOW Care Planning”	Hope others’ substituted judgment will result in patient receiving goal-concordant e-o-l care.
Proxy’s/agent’s instructions based on reporting previous verbal discussions with patient	Hope provider will believe proxy/agent that patient truly wants stated treatment of last resort *without clear and convincing evidence*.
Traditional living will	Hope proxy/agent can persuade provider that “harm outweighs benefit" here means “Cease assisted feeding” or “Moderate Anesthesia.”
Dr. Gaster’s dementia-specific” living will low controversy, highly acceptable but ineffective	Hope withdrawing all medical treatments will suffice to reduce patients’ suffering.
Typical "dementia-specific” living wills—even if there are no other flaws (which is rare)	Hope patient does not need to wait to become dependent on assisted feeding and hydrating.
Caring Advocates’ “Natural Dying Living Will” generated by responding to “My Way Cards”	**Confidence** from adding Moderate Anesthesia to reduce Dementia Gap patients’ suffering.

One major challenge and source of conflict is paternalism = when authorities act as if they know what's best for you—despite what you think.

Physicians, nursing home administrators, and others, most of whom mean well, may also have their own agendas. If they exert their authority to help you as THEY—not you—feel is right, these general consequences are possible:

They will not be respecting you as a person, not honoring your living will, and not upholding the bioethical principle of autonomy. Their actions may prolong and increase your suffering. Instead of providing you benefit, they can cause harm. They may also waste your family's assets and use society's scarce medical resources in an unfair way.

Summary: They violate the four principles of medical ethics.

One of three Americans will die with dementia. The cumulative life-time prevalence is 42%. (Higher especially for black women.)

They face four challenges to attain a timely & peaceful dying

Challenge #1: Losing decision-making capacity

(**DMC**) years before they die, making 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 to make them morally acceptable

  so they can be effective

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.

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 oral feeding and hydrating (which ibehavior is very different from eating and drinking).

Why is advanced dementia so challenging?

Clinical and moral arguments for Natural Dying:

For the unique circumstance of suffering with late-stage dementia:

➔ Feeding ≠ Loving, and Food ≠ Love.

As dementia progresses, at some point assisted oral feeding and hydrating becomes:

➔ **Unnatural** (patients would not feed themselves),

➔ **Forced** (if living wills state, “It’s unwanted”), and

➔ **Unethical**.

ALL “Dementia-Specific” living wills have flaws that could cause dying to be 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 the categories of process, content, inherently, or 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 a second, unique order: **"Always place food and fluid within patient's reach**," to uphold the highest legal, ethical, and **moral** standards.

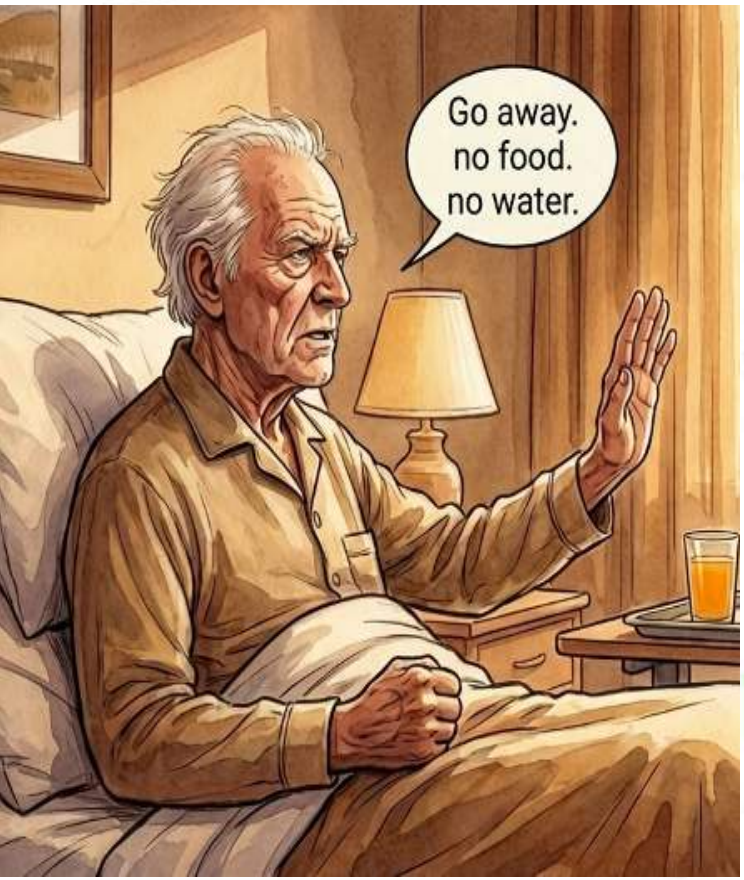
The moral argument: the goal was not to hasten dying. Patients died from their underlying brain disease because they could not recognize food &fluid, or direct their hands to put them in their mouth.

Challenge #3: Patient can eat & drink without assistance

While preserving any Activity of Daily Life is usually positive, patients living with advanced dementia who can eat and drink without assistance may have prolonged dying with prolonged suffering. They may live in a **therapeutic desert**.

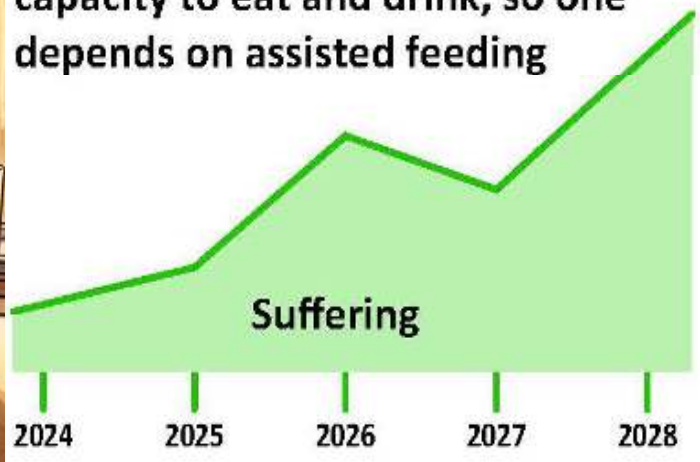
How this happens: patients' decline in mental functioning progresses more rapidly than their decline in physical capabilities.

Patients may need to wait months or years because it is not legal, ethical, or moral to withhold food and fluid. Others can view it as **illegal euthanasia**.



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 mental capacity*, articulate
Knows what he wants

Lacks capacity, inarticulate
May not recognize food and fluid

***Capacity = has knowledge, can appreciate, uses reasoning, can articulate decision for treatment**

“Ceasing assisted feeding” cannot work for patients who are **not** dependent on assisted feeding.

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

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

Alternate treatment of last resort

Moderate Anesthesia (MA) provides sedation to unconsciousness for patients who meet these criteria:

(1) Live in the “Dementia Gap”
(2) Have intolerable suffering that
(3) Failed to get relief from less-sedating treatments
(4) Are willing to sign a consent form explaining the risks.

Challenge #4: Non-Observable Suffering (N-O-S)

In epidemiology, the "iceberg phenomenon" means the observable burden of disease (above water) is dwarfed by non-observable suffering (N-O-S) burden (below water).
While the percent of N-O-S is not known, but likely much less than 90%, its reasonable to estimate about 50%.
I recently estimated 500,000 Americans currently live in the Dementia Gap with intolerable suffering.
The problem: physicians do not treat what they cannot see.
(Later: how I initially discovered N-O-S; how I routinely ask planning principals to identify it.) From our 2024 publication➔

(Please read before or after the presentation)

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

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. In addition to being clinically appropriate and legal…

For those in authority to **accept** the treatment, they must also be able to **view** the treatment as **moral**.

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.

Reducing suffering by Natural Dying and by 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. For Patients Experiencing Intolerable Suffering in the "Dementia Gap"—A Newly Defined Substage of Late-Stage Alzheimer's Disease—Can Sedation to Unconsciousness be Moral?

(*Work in progress)

Another unique feature of the "My Way Cards" protocol:

➔ It does not ask the "IF/THEN Question" (since 1969):

"If you reached *this* condition, then *what treatment* would you want?"

➔ Instead, it asks:

"How much suffering do you **judge** this condition would cause you and your loved ones?"

➔ Judging is **easier** since four choices are presented ➔

For each condition, planning principals JUDGE one of these 4 levels of suffering:

Mild suffering

Tolerable suffering

Severe suffering

Intolerable suffering

Each corresponds to a different level of POLST care

Caring Advocates' protocol generates Natural Dying Living Wills based on patients' judgments of intensity of suffering (**JIS**). Before signing this document that will become durable after loss of capacity, planning principals and ACP counselors collaborate on the unique "**Deliberative Capstone Review**." This may prevent years of conflict and guilt and lead to decreased trust—as occurred in the infamous **Dutch advanced dementia "coffee euthanasia case**."

Judged Intensity of Suffering (JIS) that a Condition Would Cause Determines ➔	Which Treatment (POLST) is expressed as desired in Your "Natural Dying Living Will"
Intolerable suffering	**MA-POLST** (Moderate Anesthesia)
Severe suffering	**ND-POLST** (Natural Dying)
Tolerable suffering	**SLT-POLST** (Selective/Limited)
Mild suffering (from dementia or another terminal illness)	**CPRL-POLST** (1 last CPR, then SLT)–unless patient's status is DNR

“Judging suffering” preferred over “deciding treatment”:

1. Much less likely that future treating physicians can override patients’ autonomy or not honor their wishes
2. It uses POLST—the most powerful e-o-l form available
3. It makes it easier for patients to respond if their cognitive ability or healthcare literacy is borderline.
4. Likely generates a more accurate reflection of their end-of-life wishes since they may not understand treatment details.
5. May prevent deciding on a life-determining event where there is mild suffering or joy is present (but needs research).

Colorado's "MOST" prioritizes patients' wishes (Highlights of this excellent form are below:)

- Other providers and facilities **shall** comply even if the form is executed in another state.
- Providers have a **duty to comply** with the orders, and they have **immunity** if they do.
- Orders can be **revised only** after obtaining consent from the patient or surrogate.
- If the provider or facility cannot comply, they **must arrange to transfer the patient** to another provider or facility.
- In the absence of a provider signature, however, the patient selection should be considered as **valid** documented patient preferences for treatment. (But may not legal impose a duty to follow.)
- Provider **need not be** on staff of the local healthcare institution.
- CO honors forms from other states. To sign a new CO MOST, **telehealth registration** satisfies the authority requirement (only takes a few weeks).

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Colorado Medical Orders for Scope of Treatment (MOST)

- **FIRST follow these orders, THEN contact Physician, Advanced Practice Nurse (APN), or Physician Assistant (PA) for further orders if indicated.**
- These Medical Orders are based on the person's medical condition & wishes.
- If Section A or B is not completed, "full treatment" for that section is implied.
- May only be completed by or on behalf of a person 18 years of age or older.
- **Everyone shall be treated with dignity and respect.**

Legal Last Name		
Legal First Name/Middle Name		
Date of Birth		Sex
Hair Color	Eye Color	Race/Ethnicity

In preparing these orders, please inquire whether patient has executed a living will or other advance directive.
If yes and available, review for consistency with these orders and update as needed. (See additional instructions on page 2.)

A (Check one box only)

CARDIOPULMONARY RESUSCITATION (CPR) ***Person has no pulse and is not breathing.***

☐ **Yes CPR: Attempt Resuscitation** ☐ **No CPR: Do Not Attempt Resuscitation**

NOTE: Selecting "Yes CPR" requires choosing "Full Treatment" in Section B.
When not in cardiopulmonary arrest, follow orders in Section B.

B (Check one box only)

MEDICAL INTERVENTIONS ***Person has pulse and/or is breathing.***

☐ **Full Treatment**—primary goal to prolong life by all medically effective means:
In addition to treatment described in Selective Treatment and Comfort-focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Transfer to hospital if indicated. Includes intensive care.

☐ **Selective Treatment**—goal to treat medical conditions while avoiding burdensome measures:
In addition to treatment described in Comfort-focused Treatment below, use IV antibiotics and IV fluids as indicated. Do not intubate. May use noninvasive positive airway pressure. Transfer to hospital if indicated. Avoid intensive care.

☐ **Comfort-focused Treatment**—primary goal to maximize comfort:
Relieve pain and suffering with medication by any route as needed, use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location.

Additional Orders:

C (Check one box only)

ARTIFICIALLY ADMINISTERED NUTRITION *Always offer food & water by mouth if possible.*

Any surrogate legal decision maker (Medical Durable Power of Attorney, MDPOA, Proxy-by-Statute, guardian, or other) must follow directions in the patient's living will, if any. Not completing this section *does not* imply any one of the choices. Further discussion is required. **NOTE:** *Special rules for Proxy-by-Statute apply; see reverse side ("Completing the MOST form") for details.*

☐ Artificial nutrition by tube long-term/permanent if indicated
☐ Artificial nutrition by tube short-term/temporary only. (Specify goal/term & goal in "Additional Orders")
☐ No artificial nutrition by tube.

Additional Orders:

D

DISCUSSED WITH (check all that apply):

☐ Patient
☐ Agent Under Medical Durable Power of Attorney
☐ Proxy-by-Statute (per C.R.S. 15-18.5-103(5))
☐ Legal guardian
☐ Other:

SIGNATURES OF PROVIDER AND PATIENT, AGENT, GUARDIAN, OR PROXY-BY-STATUTE AND DATE (MANDATORY)

Significant thought has been given to these instructions. Preferences have been discussed and expressed to a healthcare professional. This document reflects those treatment preferences, which may also be documented in a Medical Durable Power of Attorney, CPR Directive, living will, or other advance directive attached if available. To the extent not previously completed, advance directives do not conflict with these *Medical Orders for Scope of Treatment*, this document is full force and effect.

If signed by surrogate legal decision maker, preferences expressed must reflect patient's wishes as best understood by surrogate.

Patient/Legal Decision Maker Signature (Mandatory)	*Name (Print)*	*Relationship if Decision Maker (Other Than "Self") (Optional)*	*Date Signed (Mandatory, Unless a Previous MOST Form)*

Physician / APN / PA Signature (Mandatory)	*Print Physician / APN / PA Name, Address, and Phone Number*	*Date Signed (Mandatory)*
Colorado License #:		

HIPAA PERMITS DISCLOSURE OF THIS INFORMATION TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

Authority for this form and process is granted in C.R.S. 15-18.7 Directive Concerning Medical Orders for Scope of Treatment, effective 2010.

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

ADDITIONAL INFORMATION: *Please provide contact information below in case follow up or more information needed.*

Patient Legal Last Name	*Patient Legal First Name*	*Patient Middle Name (if any)*	*Patient Date of Birth*
Primary Contact Person for the Patient	*Relationship (Agent for MDPOA, Proxy, Guardian)*	*Phone Number/Email/Other contact information*	
Healthcare Professional Preparing Form	*Preparer Title*	*Phone Number/Email*	*Date Prepared*
Patient Primary Diagnosis	*Hospice Program (if applicable) Address*		*Hospice Phone Number*

DIRECTIONS FOR HEALTH CARE PROFESSIONALS

For more information, please go to: https://www.civhc.org/programs-and-services/most-program/

Completing the MOST form:

- MOST form master may be downloaded from https://www.civhc.org/programs-and-services/most-program/ and photocopied onto Astrobrights® "Vulcan Green" or "Terra Green" 65lb paper. This special paper is strongly encouraged but not required.
- The form must be signed by a physician, advanced practice nurse, or physician assistant to be valid as medical orders. Physician assistants must include physician name and contact information. In the absence of a provider's signature, however, the patient selections should be considered as valid, documented patient preferences for treatment.
- Verbal orders are acceptable with follow-up signature by physician, advanced practice nurse, or physician assistant in accordance with facility policy, but not to exceed 30 days.
- Completion of the MOST form is *not* mandatory. "A healthcare facility shall not require a person to have executed a MOST form as a condition of being admitted to, or receiving medical treatment from, the healthcare facility" per C.R.S. 15-18.7-105.
- Patient preferences and medical indications shall guide the healthcare professional in completing the MOST form.
- Patients with capacity should participate in the discussion and sign these orders; a healthcare agent, Proxy-by-Statute, or guardian may complete these orders on behalf of an incapacitated patient, *making selections according to patient preferences, if known.*
- "Proxy-by-Statute" is a decision maker selected through a proxy process, per C.R.S. 15-18.5-103(6). Such a decision maker may not decline artificial nutrition or hydration (ANH) for an incapacitated patient without an attending physician and a second physician trained in neurology certifying that "the provision of ANH is merely prolonging the act of dying and is unlikely to result in the restoration of the patient to independent neurological functioning."
- Photocopy, fax, and electronic images of signed MOST forms are legal and valid.

Following the Medical Orders:

- Per C.R.S. 15-18.7-104: Emergency medical personnel, a healthcare provider, or healthcare facility *shall* comply with an adult's properly executed MOST form that has been executed in this state or another state and is apparent and immediately available. The fact that the signing physician, advanced practice nurse, or physician assistant does not have admitting privileges in the facility where the adult is receiving care does not remove the duty to comply with these orders. Providers who comply with the orders are immune from civil and criminal prosecution in connection with any outcome of complying with the orders.
- If a healthcare provider considers these orders medically inappropriate, she or he should discuss concerns with the patient or surrogate legal decision maker and revise orders only after obtaining the patient or surrogate consent.
- If Section A or B is not completed, full treatment is implied for that section.
- Comfort care is never optional. Among other comfort measures, oral fluids and nutrition must be offered if tolerated.
- When "Comfort-focused Treatment" is checked in Section B, hospice or palliative care referral is strongly recommended.
- If a healthcare provider or facility cannot comply with these orders due to policy or ethical/religious objections, the provider or facility must arrange to transfer the patient to another provider or facility and provide appropriate care until transfer.

Reviewing the Medical Orders:

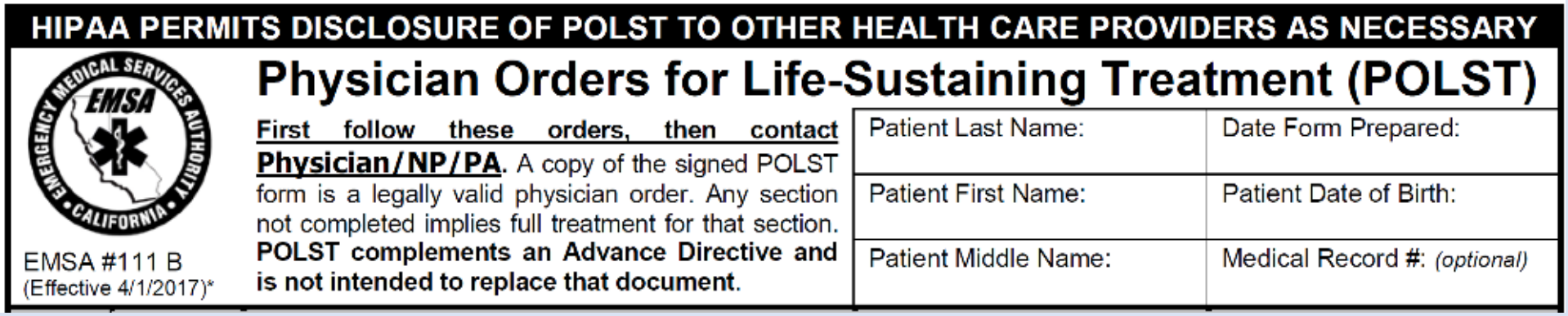
- These medical orders should be reviewed:
  - regularly by the person's attending physician or facility staff with the patient and/or patient's legal decision maker;
  - on admission to or discharge from any facility or on transfer between care settings or levels;
  - at any substantial change in the person's health status or treatment preferences; and
  - when legal decision maker or contact information changes.
- If substantive changes are made, please complete a new form and void the replaced one.
- To void the form, draw a line across Sections A through C and write "VOID" in large letters. Sign and date.

REVIEW OF THIS COLORADO MOST FORM

Review Date	Reviewer	Location of Review	Review Outcome
			☐ No Change ☐ New Form Completed
			☐ No Change ☐ New Form Completed
			☐ No Change ☐ New Form Completed
			☐ No Change ☐ New Form Completed

HIPAA PERMITS DISCLOSURE OF THIS INFORMATION TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

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)
- Have 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 two strategic orders (unique):

- Insists only patients can change POLST, so it is durable/irrevocable
- Insists orders be consistent with Living Will, so it "should" fulfill goal-concordant end-of-life care—making ACP mission possible!

How does switching to another Future POLST occur?

➔ Any concerned individual can request the members of the Patient Decision Committee meet to discuss changing POLSTs

➔ Members compare patient's current condition with the qualifying conditions for treatments of last resort expressed in patients' living will

➔ If they believe the patient has reached qualifying conditions, then the **agent/proxy/*legal decision-maker*** engages the treating provider in a "POLST Conversation." The goal is to replace the current POLST with the clinically appropriate, legal, ethical, and moral **FUTURE POLST**

➔ If the treating provider agrees, treatment of last resort to reduce end-of-life suffering can begin by implementing the new POLST.

Why are illustrations so important? – 1

- Clarify and make it easier to **understand** conditions
- Add relevant clinical **detail**
- Depict patients' and families' **emotional** responses
- **Resonate** deeply with planning principals' emotions
- Provide **common ground** for translation to other languages

Acknowledgments: Color images resulted from collaborating with Coley Perry, an AI illustrator at Coley@CLS.studio. (Now retired illustrator William Young's are appreciated for his efforts since 2009 as he helped create original and revised versions of the line drawing versions of these conditions.)

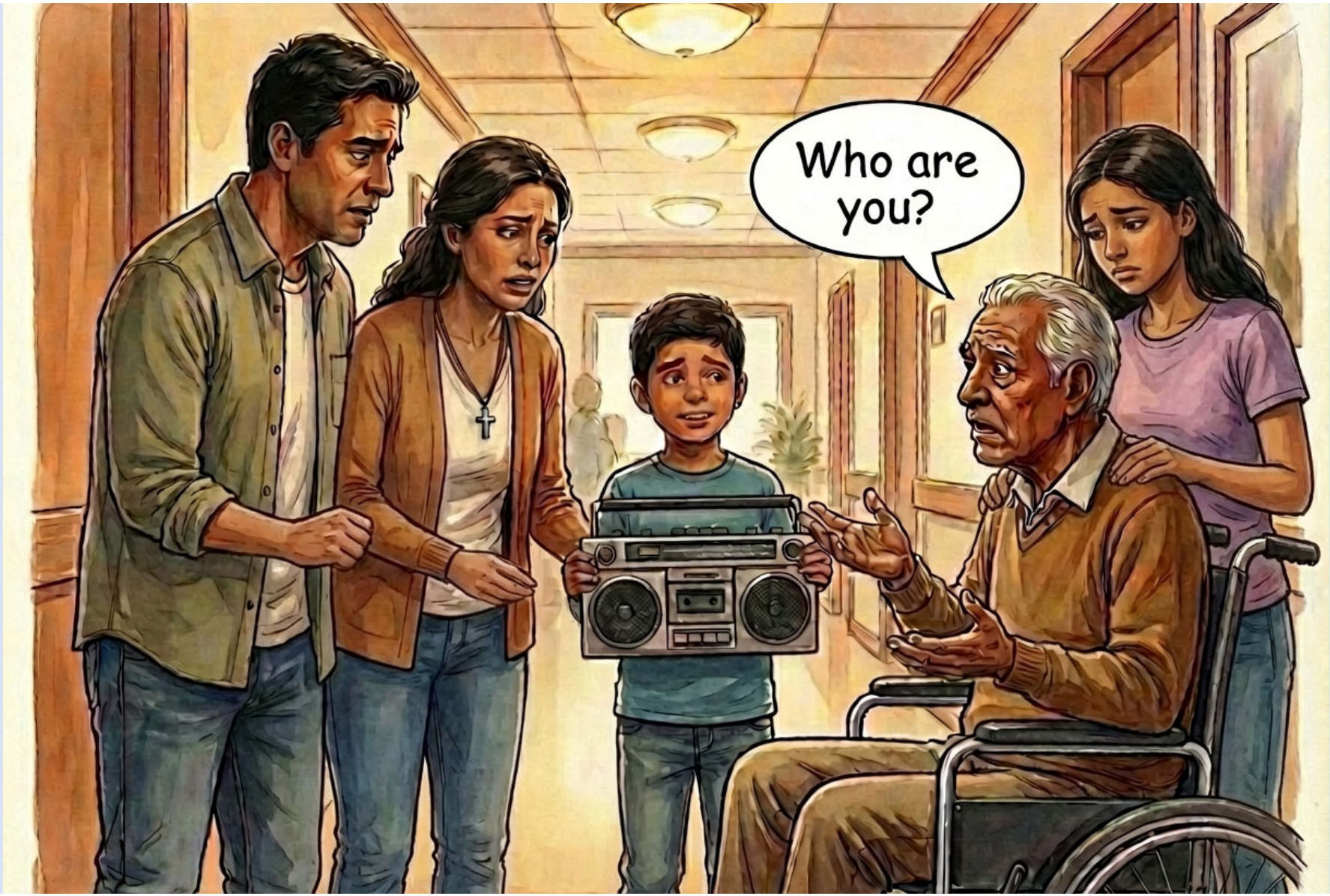
Why are illustrations so important? – 2

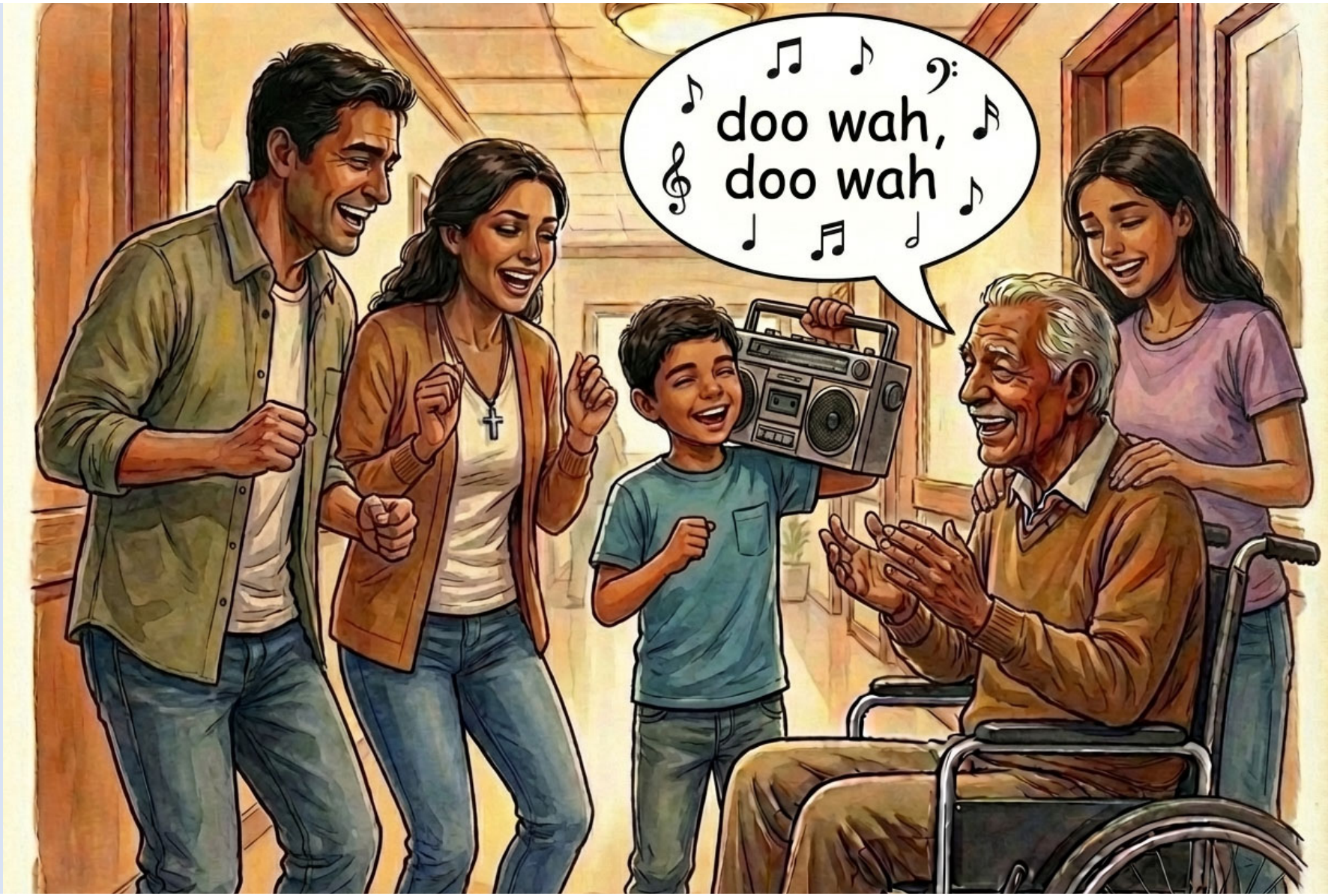
They can reveal Non-Observable Suffering (N-O-S) in two ways:

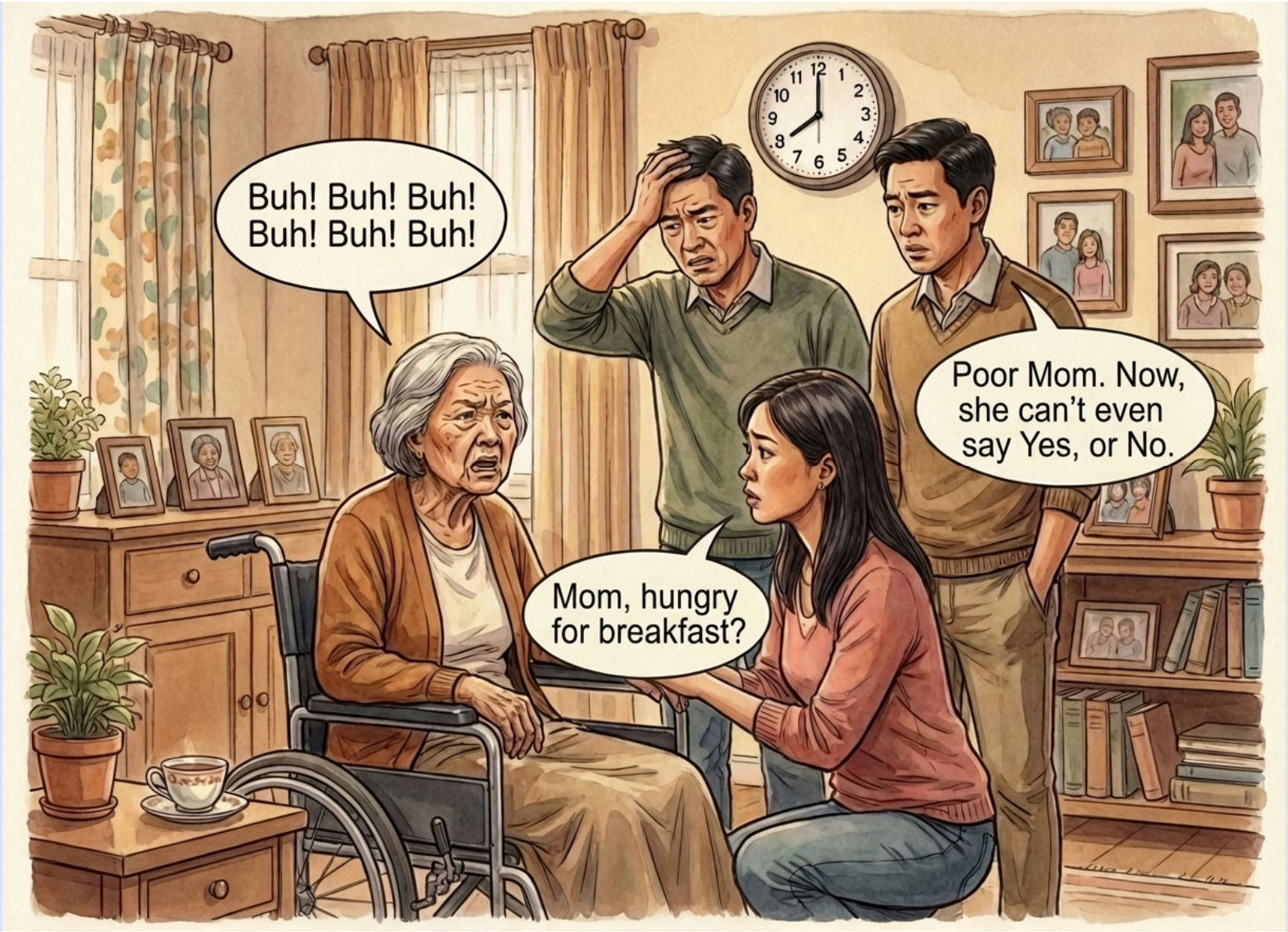
(1) Facial expressions reveal people's general inner feelings.
(2) What they say (in a word cloud) and especially what they think (in a thought cloud) more specifically reveal the source(s) of their N-O-S.

If the verbal description, image, and/or word/thought bubbles resonate with types of suffering that the planning principal wants to avoid, then they can indicate by judging the intensity of suffering they would cause.

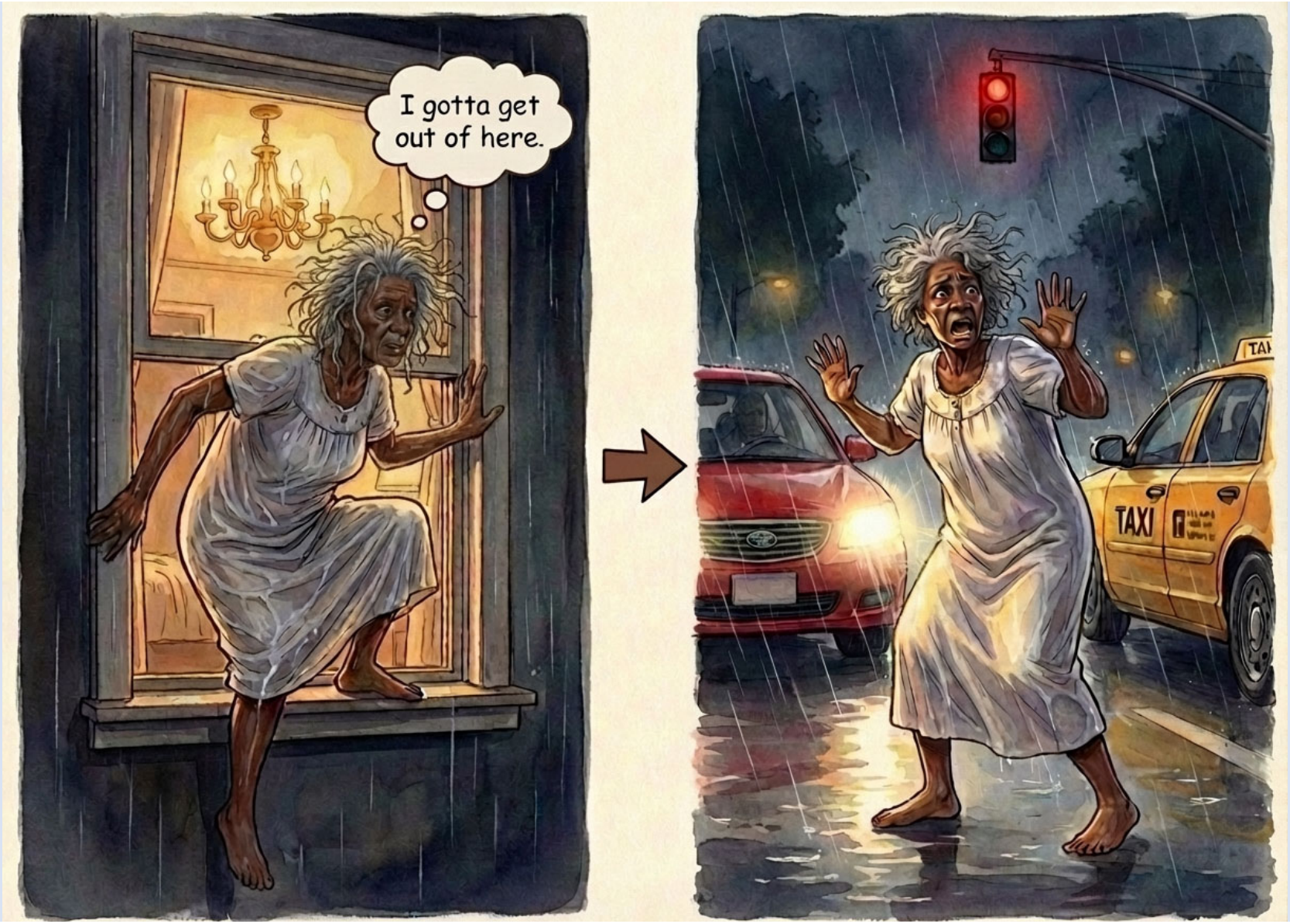
Six conditions that AK had:


Who are you?

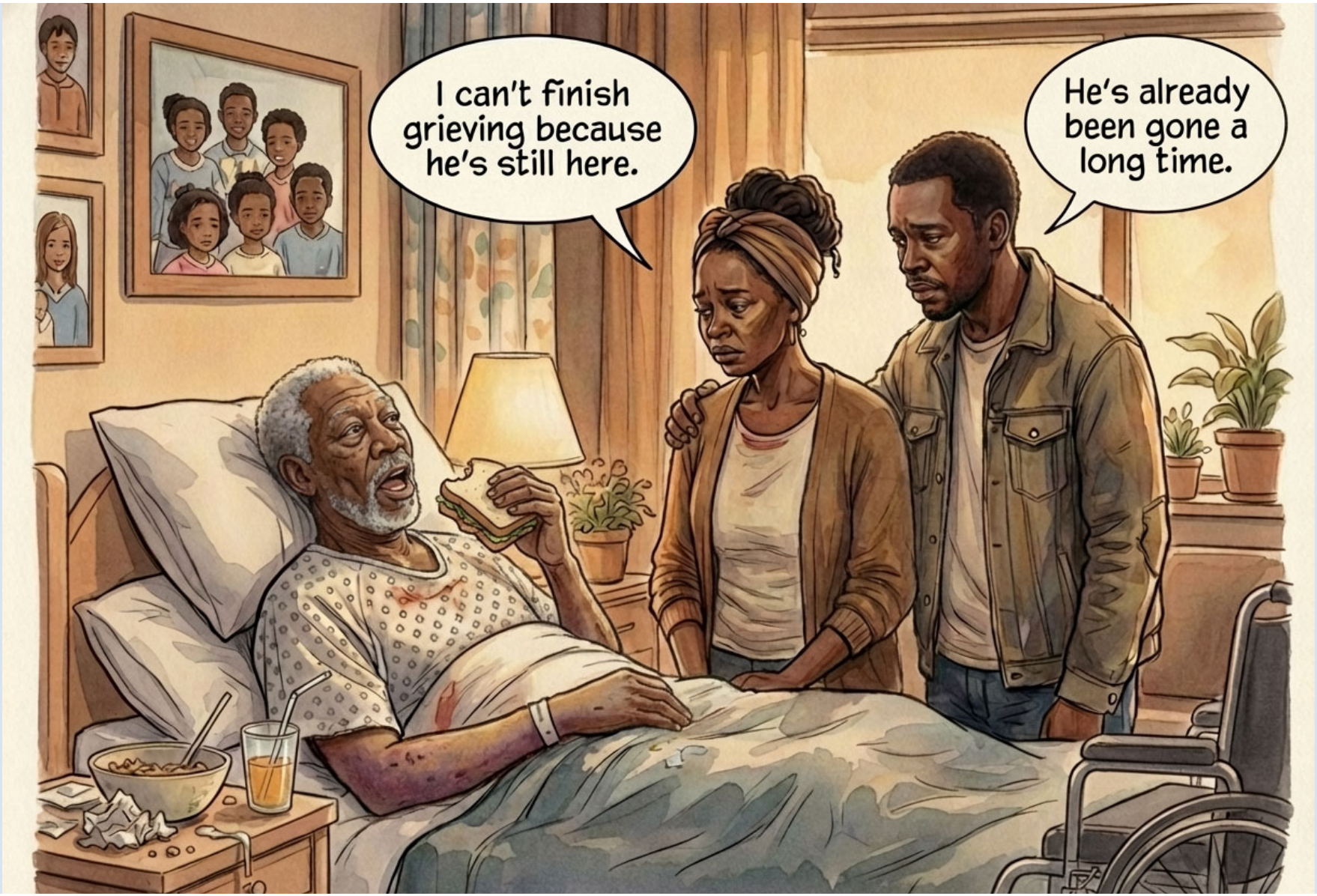

doo wah,
doo wah


Buh! Buh! Buh!
Buh! Buh! Buh!
Mom, hungry for breakfast?
Poor Mom. Now, she can't even say Yes, or No.


THIS ISN'T ME.
DIAPERS


I gotta get out of here.
TAXI


LEAVE ME ALONE!
Stop bothering me.
Call for help?


I can't finish grieving because he's still here.
He's already been gone a long time.

Two other conditions that AK did not have, but are common.

They reveal the dangers of unappreciated **Non-Observable Suffering (N-O-S)**.


Help Me. Help Me.
Help Me. Help Me.
She always says that.

Interpretation: Clinical staff's feelings about a patient who repetitively says, "Help me," can be bored, frustrated, even angry; and can lead to **abandoning** her, **dismissing** her complaints, or **distancing** from her. Living wills that include state and illustrate this possibility may prevent it.

The "**She's just sitting there; she's not really suffering,**" is the **dismissive non-sequitur fallacy**" which reduces incentives to investigate and treat Non-Observable Suffering (N-O-S). At worst, it can leave patients with lifelong suffering.


Why can't my doctor see that I am in pain?
??

There are four strategic documents that will ideally be completed, recorded on video, and notarized by a jurat:

1. Natural Dying Living Will (from My Way Cards)
2. Bilateral durable power of attorney for healthcare decisions (includes forming PDC)
3. Natural Dying Agreement (includes strategies)
4. “Future POLSTs” (between 4 and 9)

Helping incapacitated patients who lack an effective living will

For dementia patients who lack an effective living will, agents/surrogates use "**NOW Care Planning**."

The current agent and alternates can use their **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 the patient had been asked before losing DMC.

NOW Care Planning—for those who are already living with advanced dementia without an effective living will:

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

To my knowledge, it is the best legal, ethical, and moral approach available to deal with their clinical challenges.

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

Then, members discuss and vote.
(AK had SACP in 2019 except for Moderate Anesthesia, which her PDC decided by NCP in 2023. (Hybrid.)

The **Natural Dying Living Will** has a broadened view of suffering: **five sources** (from our 2024 article)

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)

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

SUMMARY: Unique or new features of Strategic Advance Care Planning:

1. The **Dementia Gap** exists; therefore, **Moderate Anesthesia** (MA) is needed to relieve patients' suffering; otherwise, they will wait in a therapeutic desert until they lose their ability to self-feed and self-drink
2. **Non-observable suffering** (N-O-S) exists; therefore, planning principals should be asked to **identify** sources during ACP—otherwise, inarticulate patients may be forced to endure severe or intolerable suffering until they die

SUMMARY: Unique or new features of Caring Advocates' Strategic Advance Care Planning:

3. During advance care planning (ACP), planning principals do not need to make decisions about medical treatments that they may not understand for each of 40 conditions. Instead, they only need to **JUDGE** the intensity of suffering (JIS) for each condition based on their lifelong values and treatment preferences. They have four choices: mild, tolerable, severe, or intolerable.

4. The primary actionable end-of-life document is not the agent's instructions backed by the written/video living will. Instead, it is the **Future POLST** that the planning principal discussed and signed during ACP—which must be consistent with the living will.

Successful ACP: An operational definition

After members of the Patient Decision Committee (PDC) reach a consensus of substituted judgment (CSJ) that the patient fulfills the clinical criteria for a treatment of last resort, the agent presents a new Future POLST to the treating physician/provider who—without conflict, promptly administers it to reduce patient's suffering. The result: (A) patients have a peaceful and timely dying and (B) loved ones' suffering is minimized.

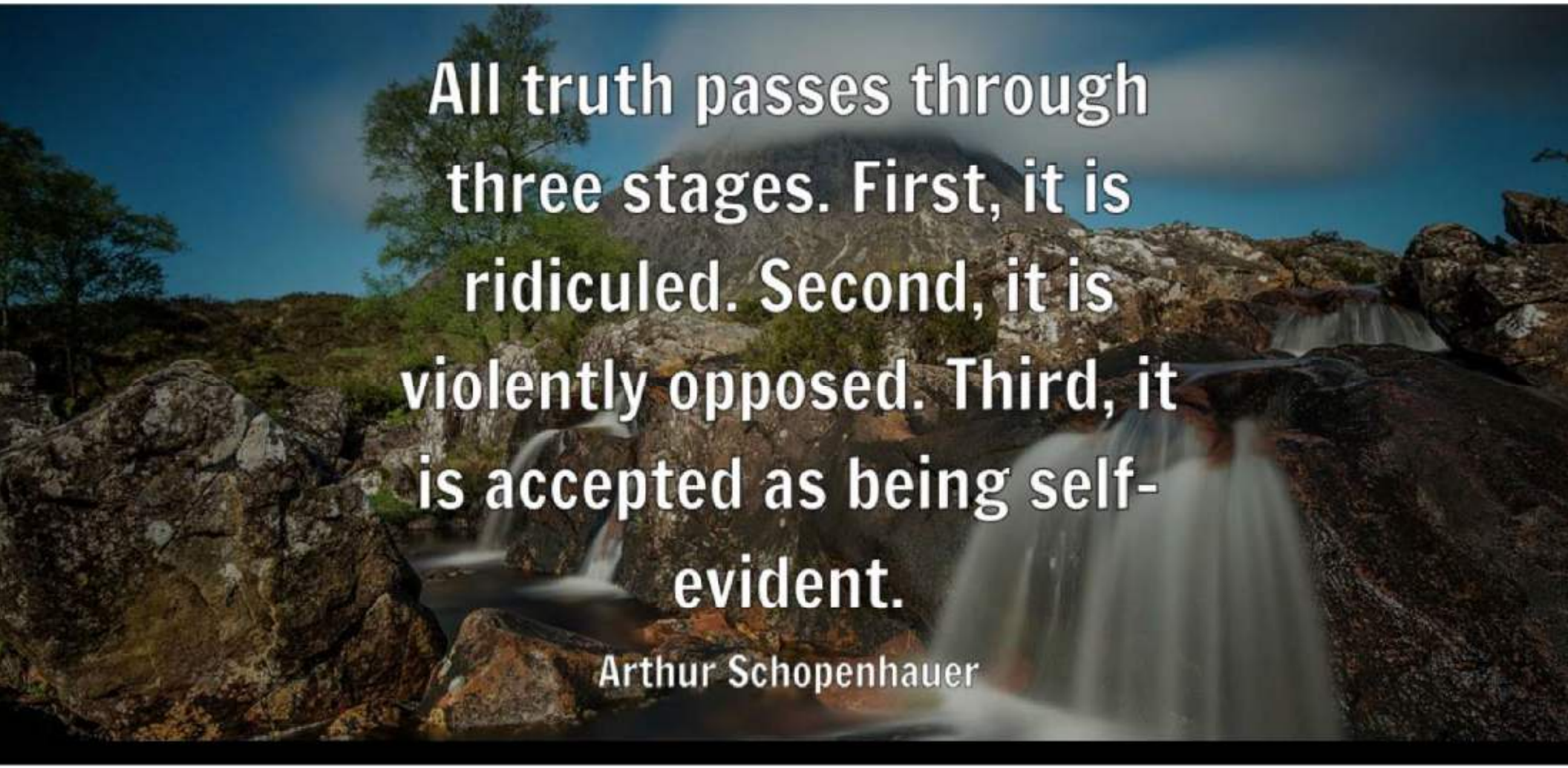
From Hope to Confidence: From Least to Most Diligent, Comprehensive, and Likely Successful Advance Care Planning for Dementia	
Extent of Advance Care Planning	**Is Hope or Confidence Warranted?**
No ACP, lacks decision-making capacity, so the only option is “NOW Care Planning”	Hope others’ substituted judgment will result in patient receiving goal-concordant e-o-l care.
Proxy’s/agent’s instructions based on reporting previous verbal discussions with patient	Hope provider will believe proxy/agent that patient truly wants stated treatment of last resort *without clear and convincing evidence*.
Traditional living will	Hope proxy/agent can persuade provider that “harm outweighs benefit" here means “Cease assisted feeding” or “Moderate Anesthesia.”
Dr. Gaster’s dementia-specific” living will low controversy, highly acceptable but ineffective	Hope withdrawing all medical treatments will suffice to reduce patients’ suffering.
Typical "dementia-specific” living wills—even if there are no other flaws (which is rare)	Hope patient does not need to wait to become dependent on assisted feeding and hydrating.
Caring Advocates’ “Natural Dying Living Will” generated by responding to “My Way Cards”	**Confidence** from adding Moderate Anesthesia to reduce Dementia Gap patients’ suffering.

Concluding remarks

- Late-stage dementia is horrible, but premature dying is tragic and not necessary to avoid it. There is an alternative to sacrificing enjoyable life so you can live as long as you still enjoy living.
- If you still have capacity, your call to action is **Strategic Advance Care Planning**.

Plan Now, Die Later—to Live Longer

- If your relative or close friend has already reached advanced dementia, **NOW Care Planning** may be able to reduce how much and how long they need to suffer.


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, and a revised PDF of these slides is available.

New VSED Advance Directive: Improved Documentation to Avoid Late-Stage Dementia

Published online by Cambridge University Press: **25 September 2025**

Thaddeus Mason Pope, Lisa E. Brodoff, Erin Mae Glass, Paul T. Menzel and Robb M. Miller

Pope TM, Brodoff LE, Glass EM, Menzel PT, Miller RM.

New VSED advance directive: improved documentation to avoid late-stage dementia.

J Law Med Ethics. 2025;53(3).
DOI: 10.1017/jme.2025.10176.

The Northwest Justice Project's Advance Directive for VSED Likely Offers The Best **Legal Documentation** Available.

Let's consider its **clinical criteria**—to decide WHEN to implement cessation of assisted oral feeding and hydrating ("if" condition met).

- I want to start VSED [A] when [IF] I have a serious and irreversible illness or chronic condition that will not significantly improve (even if it is not terminal),
- **and** [B] when [IF] I meet [you choose selection criteria: one or all]
- __ at least **one** of the conditions I select below. ← **Let's focus on**
- __ **all** of the conditions I select below (initial all that apply):

SPECIFIC CONDITIONS IN POPE ET AL.'S ADVANCE DIRECTIVE

- __ I cannot communicate with others beyond a few words, eye movements, etc.

  [My interpretation if I checked this: I would still want VSED –even if I can say, Yes/No, or I can look right or left to indicate Yes/No?]

- __ I do not recognize close family and friends.

  [My interpretation if I checked this: I would still want VSED if I cannot recall family members' names and genetic relationships—even if all of us could enjoy our visits (as shown in a previous image)?]

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