

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

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

Stanley A. Terman, PhD, MD; Caring Advocates
Bioethicist, Board Certified in Psychiatry
San Francisco End of Life. May 7, 2025

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 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 who made many contributions to society: the person she once was.

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 loss of capacity. It motivates to investigate 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 treatments 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.

Still be Moral, Why it Matters:

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 a physician/provider agrees to implement the orders patients need.

Physicians, other providers and their health care institutions may refuse to honor patients' wishes if they lack confidence that the living will's treatment instruction was moral.

If ACP fails, prolonged dying with suffering can result.

Still be Moral, How to gain approval:

Spend the required extra effort by attempting to prove this:

The intent of all concerned (patient during ACP, current treating physicians/providers, and others)

- Was not to hasten patient's dying
- Was instead to solely relieve patient's suffering

The Moral Principle of Double Effect

It is moral to commit an act if the intent is good,
Even if the outcome of bad is foreseen and possible,
As long as the bad outcome is not intended
And is not the means by which the good outcome is achieved.

So, if the physician's intent and patient's intent is to reduce suffering,
But there is a foreseen possibility that treatment will cause the patient to
die sooner than if treatment is not provided,
The treatment is still considered moral.

For some terminal diseases, including advanced dementia, it's not easy to die

Patients who have lost their ability to make treatment decisions, (decision-making capacity, or **DMC**), are particularly vulnerable. For advanced dementia, the percentage of patients who lose DMC approaches 100%, and can occur years before they die.

These patients **cannot**:

- Speak for themselves
- State what treatment they do or do not want now
- Revise their living will to make it current or effective
- Complete any aspect of advance care planning (**ACP**)

Other Terminal Illnesses Where Loss of Decision-Making Capacity is Important

- Cerebrovascular accidents (strokes)
- Persistent vegetative state
- End-stage renal disease
- End-stage liver disease
- Heart failure if severe
- High doses of opioid for pain (common in advanced cancer patients)

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

The elusive holy grail of living wills

One essential characteristic of living wills—ensuring 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 this field have publicly acknowledged abandoning pursuing this goal.

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

More simply: Ideally,

Want = Get

Unfortunately, the
other possibility is:

Want \neq Get

Two trends are confusing:

Ability to diagnose dementia at onset and as the cause of death are getting better

Lifestyle changes and other factors are decreasing the rate of increase in dementia

Advanced dementia has limited options if your suffering is enough to want to be allowed to die

The **first limitation** applies to patients who do not depend on high-tech treatment to live. They have **No Plug to Pull**.

Traditional living wills that are silent regarding food and fluid:

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

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

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

To be legal and moral, living wills should (but rarely) insist:

- Always offer food and fluid within reach
- Distinguish “offering” from “putting” food and fluid in the mouth
- Implement only if suffering is irreversible and severe
- Distinguish between relieving suffering and hastening death
- Argue that continuing feeding can be judged as being **unnatural, forced, and unethical** →

Forced Feeding Can Violate the Four Principles of Bioethics

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

Another limitation newly identified as important

The **second limitation** applies to patients who do not depend on others' assisting their feeding and hydrating. They retain this ability:

Some patients can still eat and drink independently

(in addition to having no plug to pull, and to being incapacitated).

To explain: the rate of progression of dementia causing loss of mental versus physical capacities varies greatly among patients.

Patients who live in the Dementia Gap

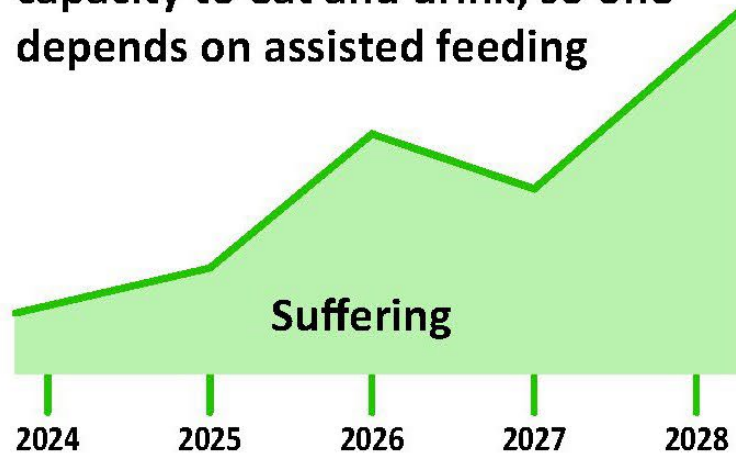
A previously unidentified substage of dementia, in which patients:

- Lack capacity
- Do not depend on assisted feeding
- Want treatment to relieve exceedingly severe suffering despite risks
- My estimate for the number of Americans currently living in the Dementia Gap is 500,000.



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



The Challenge is now well-defined:
We need a Living Will that is effective,
even for patients who live in the Dementia Gap

But first, consider how successful “dementia-specific” living wills have been, in helping patients who do have one less challenge: they depend on assisted feeding.

Are “Dementia-Specific” Living Wills Effective?

In 2022, BioMed Central published my critical review of new dementia-specific living wills, all of which had one or more of 24 identified flaws that could lead to premature or prolonged dying. This long article considers four types of flaws. Example: a living will intended for patients with early dementia required an ability to comprehend reading at grade 14 (second year of college).

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](https://doi.org/10.1186/s12910-022-00831-7)

My published critical review found most authors of living wills/advance directives completed only half the job: they included no strategies to compel physicians/providers to comply.

These authors stopped after helping patients create a clear form that could be notarized.

NO LIVING WILL was designed to help Dementia Gap patients. (Back then, neither did my living will.)

The Natural Dying Living Will:

- In continual development since 2006
- Illustrated since 2009 by collaborating with William Young
- Comprehensible at third grade reading level
- Content validity improved
- Free “Demo” online program is available

“In the illustrations, “P” means published; and
“S” means was or will be submitted for publication.

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



Purposes of illustrations:

- Clarification, easier to understand, improved content validity
- Added specific clinical detail for some conditions
- Depicted typical emotional responses of patients and family
- May importantly 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.

Introducing a living will that is designed to help reduce suffering for all patients, including those living in the Dementia Gap

I have been extensively revising this living will for two years.

*Terman SA. Timely dying for patients living in the “Dementia Gap”: If their suffering becomes exceedingly severe, is it moral to sedate them to unconsciousness? (*Work in progress)

Caring Advocates' **Natural Dying Living Will**

Now 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 always placing food and fluid within your reach—to uphold the highest legal, ethical, and moral standards.

Since food and fluid is always offered, the goal is not to hasten dying. Arguable, patient died of his/her underlying disease.

The other treatment of last resort

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

The protocol includes stopping sedating medications after about four days rest so your physician can ask, “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 frequently used term, palliative sedation to unconsciousness.

Natural Dying Living Will now offers the treatment option of sedation

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](https://doi.org/10.1002/dad2.12528)

*Terman SA. Relieving Refractory Suffering in Advanced Dementia with a Protocol for Advance Care Planning, or a Protocol for Late-Stage Patients who Lack Directives—which can be Effective, Legal, and Moral
(*Work in progress)

Examples of My Way Cards

To exemplify a range of severity of suffering,

Here are a few examples of the living will 's patient decision aid that includes 50 My Way Cards, each of which depicts a specific clinical condition, in order of increasing severity:

No / minimal suffering

Tolerable suffering

Severe suffering

Exceedingly severe suffering

The task of advance care planning:
For each of the living will's 50 conditions,
judge how much suffering it would cause.

Based on this judgment, **decide** which POLST
level of treatment you would want—if
someday, you reached this condition.

(Later in the process of ACP, you will consider
a way to handle more than one condition at a
time.)

You have four levels of treatment to decide on:

- **CPRL** if the condition would cause **mild or no suffering**.
(SLT + 1 CPR) since you still have dementia and need assisted feeding
- **Limited Treatment (SLT)** if it would cause **tolerable suffering (always DNR)**.
- **Natural Dying (ND)** if it would cause **severe suffering** (because medical dehydration is a peaceful way to die)
- **Moderate Anesthesia (MA)** if it would cause **exceedingly severe suffering** (so you will not be aware of your suffering)



Severe enough suffering



No suffering

P

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 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

He's like this all the time



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.

This requires additional effort in ACP →

Strategic Advance Care Planning's “DDDD”

- Demonstrate: memorialize wishes on video; swear a notarial jurat
- Diligent: consider your judgments of severity of suffering 3-6 times—and based them on your lifelong values and treatment choices
- Deliberative: discuss your decisions with physicians, ACP counselor, others; hold a final “Deliberative Capstone Review”
- Decision-making process and implementing strategies inspire your feeling confident about controlling (as much as possible) when and how you will have a peaceful and timely dying

Strategic Advance Care Planning requires completing Four Documents. Most are recorded on video. All are notarized by jurat:

1. Natural Dying Living Will
2. Bilateral durable power of attorney for healthcare decisions
3. Natural Dying Agreement
4. Series of completed “Future” POLSTs

A “Dear Doctor” WARNING: Why you should honor my Natural Dying Living Will.

Dear Doctor:

There are **three legal risks** if you fail to write orders that comply with my expressed, known wishes in this living will: The first is **criminal**.

Providing treatment without consent is **battery**. The second is **civil**.

Providing treatment without consent is a tort (**malpractice**). The third is **administrative (disciplinary)**. Sanctions or other adverse actions could be taken against your medical or professional license for unprofessional behavior.

Bilateral durable power of attorney excerpt:

I _____ <agent> promise to advocate <patient>'s wishes expressed when they possessed capacity—even if it now seems against the apparent desires they are 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 this Bilateral Durable POA:

Natural Dying Agreement—Table of Contents

| Section | Page |
|---|------|
| About This Natural Dying Agreement | 2 |
| Five important points I considered as I completed this form | 3 |
| DISCLAIMERS | 3 |
| My Three Goals of my Strategic Advance Care Planning | 3 |
| Overview: Why I need strategies in addition to my Natural Dying Living Will | 4 |

| Section | Page |
|---|------|
| Strategic Advance Care Planning is not for everyone | 7 |
| Strategies to overcome common challenges so I can attain my end-of-life goals | 9 |
| I. If my suffering is exceedingly severe, I consent to Moderate Anesthesia | 9 |
| II. If I have an intra-cardiac device, I want it turned off as my life is ending | 15 |
| III. If I need psychotropic medications for my behavior, administer them promptly | 16 |
| IV. I want to indicate now where I want to die if my Patient Decision | 17 |

| Section | Page |
|--|------|
| Committee (PDC) members consider it feasible | |
| V. I refuse future adult/elder care abuse investigations as I receive ND or MA | 19 |
| VI. If my future incapacitated self indicates a desire that conflicts with the decisions in my Natural Dying Living Will, I waive my legal right to object | 21 |
| VII. If a so-called "expert" alleges I changed my mind to want assisted feeding to continue, my standards must be met to continue assisted feeding | 27 |
| VIII. I insist the term, "Basic Care," is irrelevant; honor my NDWL | 28 |

| Section | Page |
|--|------|
| IX. Dismiss additional clinical criteria that some physicians may write and require before they will follow my NDLW instructions to cease assisted feeding | 30 |
| X. My series of Future POLSTs uses National POLST forms to fulfill my goals | 34 |
| Recap, further options, perspectives, and statements of conviction | 37 |
| Signature Page for my current physician (if Dr. Terman) | 39 |
| Signature Page for my patient's current physician (if not Dr. Terman) | 40 |
| Signature Page for a person who knows me and has no conflict of | 41 |

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; and all strategies 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: some strategies are available, which may suffice. And is likely the best legal, ethical, and moral approach possible.

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?” (There are 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>.)

Example of Patient Decision Committee voting results that conditions of severe suffering are exceedingly severe

| 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 <i>Existential suffering*</i> | 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 regardless of treatment setting

Additional (unique) Strategies:

- Insists only patients can change POLST → durable
- Insists orders be consistent with Living Will → effective
- 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).

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
- For any POLST where you lack capacity, your Patient Decision Committee will vote which one is clinically appropriate
- Reasons for using “National POLST” are explained elsewhere

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:

Middle Name/Initial:

Last Name:

Date of Birth (mm/dd/yyyy):

Gender:

Preferred [gov. photo ID] name, unless same:

Suffix (Jr, Sr, etc):

State where form was completed:

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 Seven Steps to Strategic Advance Care Planning

1. Patient-family/Patient Decision Committee webinar: How 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. The minimum to present a future physician/provider?
5. The pros and cons of MAiD—which requires **DMC**
6. Questions and answers
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

My overall advice is embodied in this slogan:

Plan now, die later—to live longer

Stanley A. Terman, PhD, MD
Caring Advocates

<http://caringadvocates.org/>

Information: 800 64 Peace (647 3223)

Direct cell/text: (760) 704 – 7524

DrTerman@CaringAdvocates.org

Final Points and Summary :

This is a HUGE challenge. I estimate between 1.5 and 2 million patients currently need, but do not have, an effective living will/advance directive to attain relief from severe suffering that is often not observable.

The estimated annual cost of care will soon exceed a trillion dollars a year but does not account for the human suffering of patients and their family members. One person's disease affects the lives of others, including family members who become caregivers by abandoning their professions to keep their relative alive who really would have wanted—perhaps years ago—to have a peaceful and timely dying.

A Huge Problem <move earlier>

- About 2 million (11% of those of 65) American live in advanced dementia <check, citation>
- 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](https://doi.org/10.1038/s41591-024-03340-9)