

Advance Care Planning for Dementia

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Why is dementia unique?

- Early in the disease: lose ability to guide one's own care. Others have to make decisions on your behalf, for many years.
- Course is often rough. ~ 80% go through a phase of being agitated, often combative.
- Many would want a gradual shift to comfort-focused care. But when? How to decide?



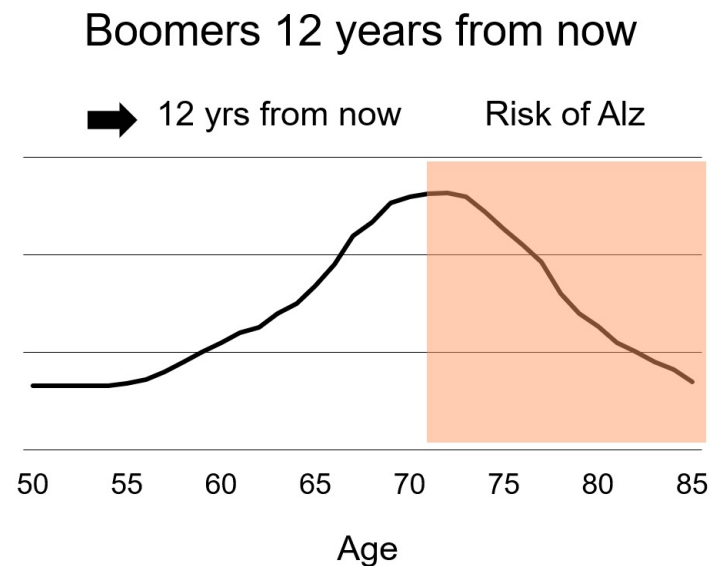
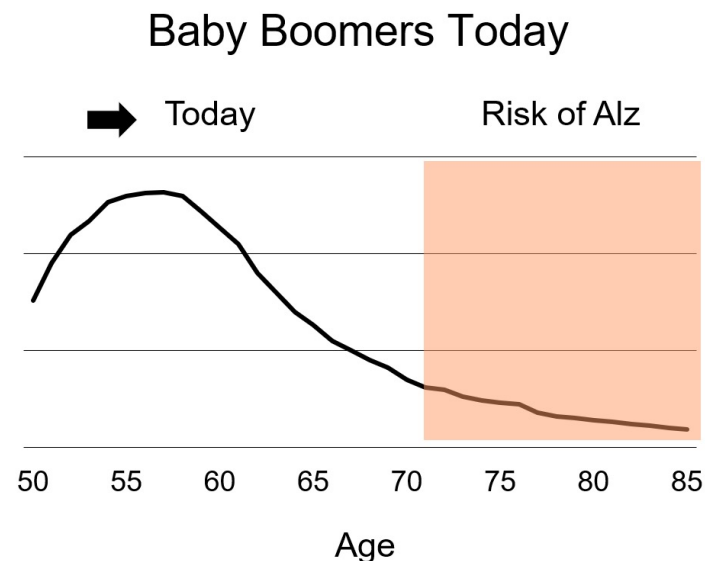
Dementia Shock Ahead

Now: 6.2 million Americans

30% of everyone over age 85

In the next 10 yrs: will ↑ 40%

Will double in the next 20 years



The #1 Disease Challenge We Face



Advance Care Planning for Dementia

Helping align medical care people get
with the medical care
they would have wanted



What's in a Standard Advance Directive?

- Almost no guidance about dementia.
- Main focus: permanent coma or persistent vegetative state.
- No guidance on #1 reason people lose decision-making capacity: **Dementia.**

But Dementia is Complex

- People with early dementia may have many years with a good quality of life.
- Often a slow decrease in quality of life: from mild, to moderate, to severe stages.
- Most people would want different goals for their medical care, along those stages.

“I’m still here”

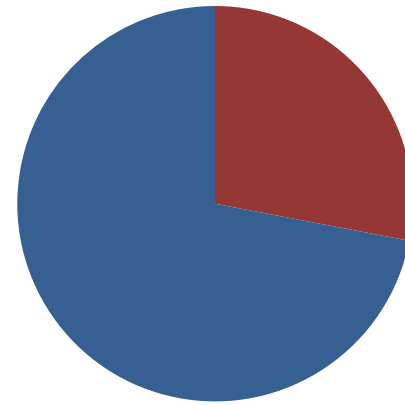


Many People Have Clear Ideas

Study of 200 people >65yo w/o dementia



- Watched balanced depictions of living with dementia



- 72% indicated they would want comfort oriented care only

**How to help people
communicate their wishes?**

Dementia-specific Advance Directive

- Developed with input from experts in palliative care, neurology, and geriatrics.
- Tested and refined in primary care.
- Available for anyone to download from:

dementia-directive.org



A Simple Way to Document the Medical Care

You Would Want If You Had Dementia

DOWNLOAD THE DEMENTIA DIRECTIVE FORM

INSTRUCTIONS

FAQS

RESOURCES

IN THE NEWS

An advance directive for dementia as featured in the [New York Times](#).

DOWNLOAD THE DIRECTIVE

Dementia-directive.org

- Brief descriptions of mild, moderate, and severe dementia.
- Below each stage, ability to choose a goals of care option for that stage:

Full code

DNR/DNI

Comfort-focus

The “Why” for Care Options

- ❑ **Full efforts to prolong life:** including CPR.
- ❑ **No CPR, no intubation:** Why might choose: people with dementia who survive, are at high risk of much worsened state if they survive.
- ❑ **Comfort-focused care only:** relieve suffering. Avoid antibiotics, avoid ER, avoid hospital unless they are needed for comfort. The why: high risk of adverse effects, complications.

My mom had Alzheimer's, she suffered for 8 years without being able to speak or understand. Having had this document would have helped our family so much.

I had to fly blind with my mom's dementia. I don't want the same thing to happen to my kids. I gave a copy of it to all my friends. Everyone should have it.

I've worked for many years with people with dementia. Your document distills the most important issues about it. It's simple and easy to use. Thank you!

Best time to offer a Dementia Directive

- ✓ Before signs of dementia occur.
- ✓ Consider: for everyone over age 65

www.dementia-directive.org

Is it “Legal?”

Legal Aspects

- Advance directives are general guides for families. They inform us of patients' values, preferences. Not a rigid algorithm.
- They are not legally binding. Instead, they are there to provide guidance for proxies and clinicians as they make decisions.

No Witness Requirements, Why?

- Witness requirements are a barrier to completion.
- If require witnesses: fewer will get done.
- The risk (of conflict/ uncertainty) if people *don't have* a directive is *greater* than the risk of conflict from an unwitnessed directive being legally challenged.
- Brilliant NEJM essay: Let's "delegalize" living wills, and not require witnesses. Different from DPOA...

- **Legal framework**: Dementia Directive can be a supplement to a Standard Advance Directive. (But OK as stand-alone also)
- **Could it be notarized?**
Yes! If someone is worried about legal challenge. But not needed. No section for notary on the form. Better chances that it'll get filled out without it on the form.



Value of a Dementia Directive

- A guide to help people express their preferences. Most importantly...
- **Communicate** them to their loved ones.
- Should never be a rigid algorithm. Biggest value: is that they facilitate memorable conversations.
- With added bonus: documentation!
Something families can look back on later.

Patients with Early Dementia

The most important form is the DPOA --- set proxy decision-makers.



Proxies (DPOA-H)

- Early in dementia: So important to designate, in a **legal form** who they would want their proxies to be.
- With alternates.
- Because over 10-15 years, their default (usually their spouse) may no longer be available to serve as their decision maker.

Having a Conversation

- Once at moderate stage: gently begin conversation: **if could look down now, what would loved one have wanted?**
- Talk about the stress and potential harms of CPR, ER trips, imaging tests.

The Invaluable POLST

The image shows a sample POLST form with a yellow background. The form is titled "POLST (Portable Order for Life-Sustaining Treatment)" and includes sections for patient information, physician information, and treatment preferences. The form is divided into several sections, each with a lettered header (A through F). Section A is for "Physician Information", Section B is for "Patient Information", Section C is for "Physician Information", Section D is for "Patient Information", Section E is for "Physician Information", and Section F is for "Patient Information". The form includes checkboxes for "Do Not Resuscitate", "Full Resuscitation", "Comfort Care", and "ICU Care".

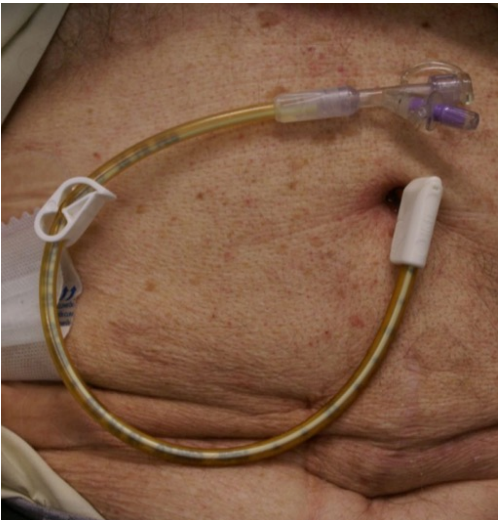
- **P**ortable **O**rder **L**ife **S**ustaining **T**reatment
- A crucial tool: anchors goals of care conversations. Invaluable communication across sites.
- Sets goals of care **now**: What if heart stops. Or can't breathe on own. Is the preference for: comfort care? ICU care?

Remember the “Why”

- ❑ **No CPR, no intubation:** Why might choose: People with dementia, who survive, are at high risk of being in a worsened state if they survive.
- ❑ **Comfort-focused care:** Symptom relief only. Why: High risk of adverse effects, of agitation, more complications from many interventions.

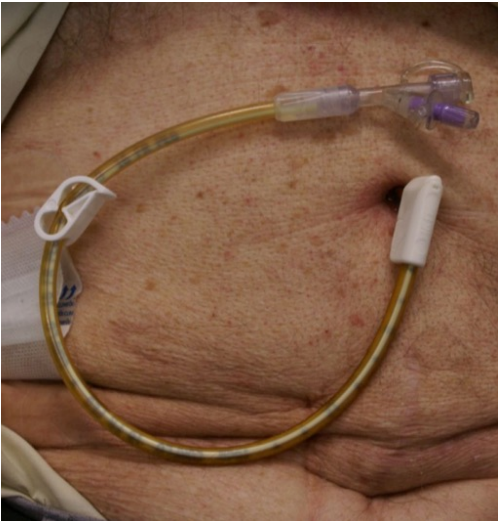
“Imagine if your loved one could look on themselves now, what might they say they’d want?”

What About Tube Feeding?



- In dementia: feeding tubes do more harm than good.
- Strong expert guidelines, solid data-driven research.
- They don't make people more comfortable, don't prolong life, they cause more aspiration pneumonia, more suffering.

Tube Feeding Does Harm



- We know this. But families usually don't. The challenge: how to have this conversation in a caring, empathic way.
- Suggested wording: "Tube feeding does not fix what is a slow dying process. It's been shown to make people less comfortable." "I worry that..."

Key Points: Advance Care Planning

- **Before dementia:** To everyone over age 65, offer a dementia directive: Dementia-directive.org
- **Mild dementia:** fill out a DPOA-HC proxy document (with alternates) as soon as possible.
- **Mod/severe dementia:** POLST appropriate and valuable
- **Key phrase:** “Imagine if your loved one could look on themselves now, what might they say they would want?”

The Medicare Annual Wellness Visit

- AWW still a valuable, useful tool for patients with dementia. Still a “free” annual visit for your patients.
- Preventive Screening is less important as life expectancy shortens, so it’s a useful shift: use AWW time to talk about Advance Care Planning.
- **Important tip:** There is an easy to add billing code for Advance Care Planning (at an AWW.)
- Adding this code doubles the RVU’s for an AWW.

Adding Advance Care Planning billing code to an AWW

- If you spend >15 minutes discussing advance care planning at an AWW – such as discussing dementia directive, DPOA, and/or POLST, just add a simple billing modifier.
- Increases the RVU for the visit from 1.5 to 3.0
- And there's no additional cost to the patient. (No additional co-pay, no deductible.)

Adding ACP billing code to an AWW

Documentation for billing is very simple:

Patient would like DPOA to be <spouse>.

Patient preference, if cardiac arrest then:
<full code> or <DNR>. Forms on file are: ____.

I spent ____ minutes face to face with patient
discussing preferences for future care.

This wording, and the codes to use, are on a 1-page easy
handout: **www.Cognition-PrimaryCare.org**

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Dementia-directive.org