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?

Front Neurol. 2012; 3: 73. PMID: 22586419

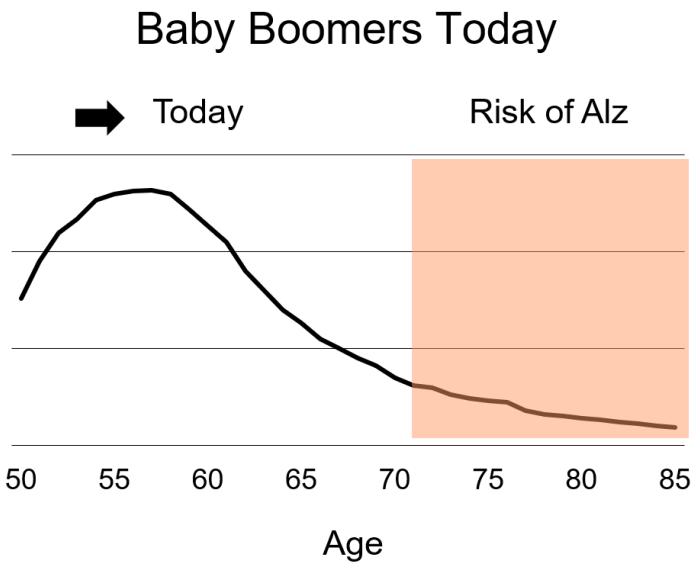
Dementia Shock Ahead

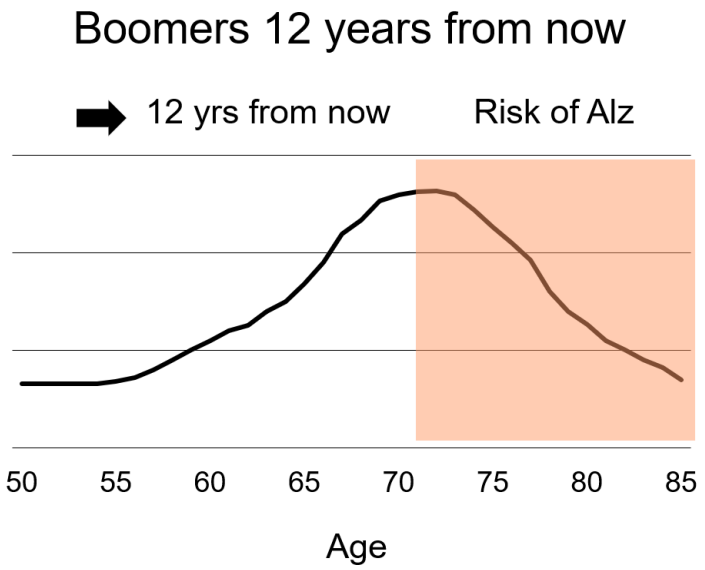
Now: 6.2 million Americans

30% of everyone over age 85

In the next 10 yrs: will ↑ 40%

Will **double** in the next 20 years





Alzheimer's Dementia 2021;17:327-406.

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.

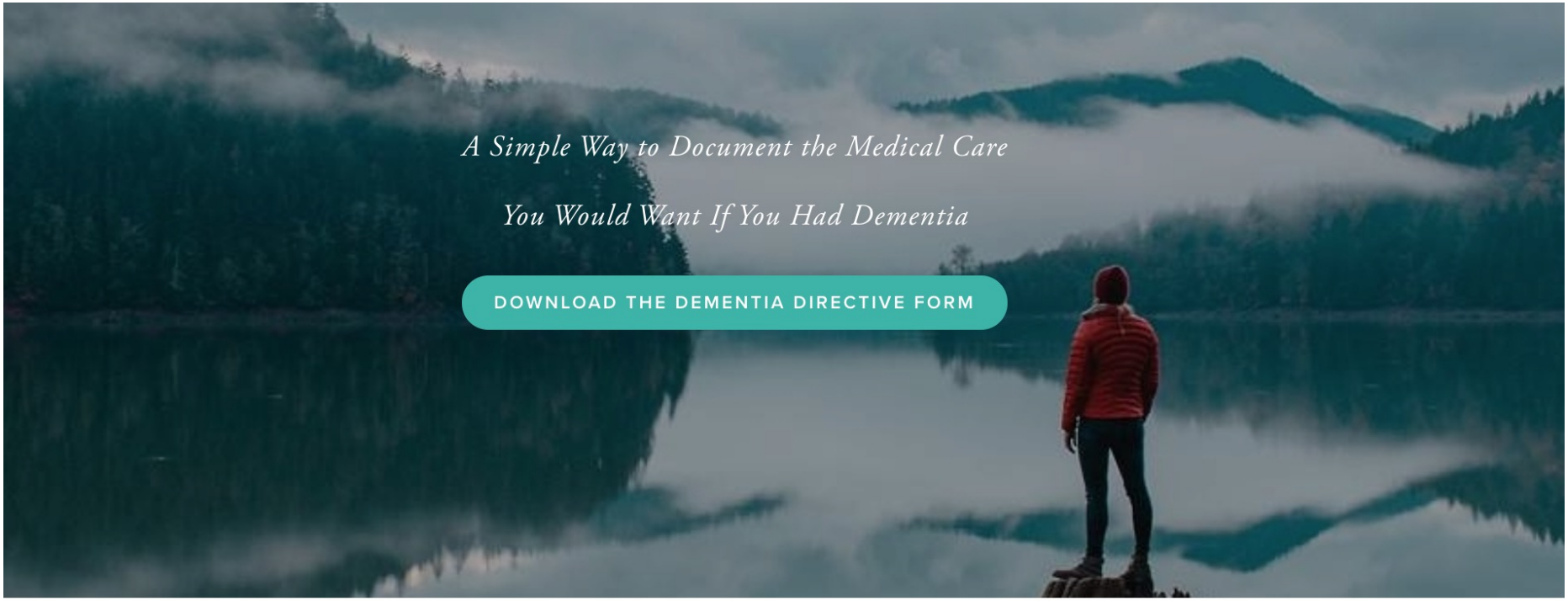
How to help people communicate their wishes?

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

JAMA. 2017;318(22):2175–2176



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

JAMA. 2017;318(22):2175–2176

Describes the three stages of dementia

- **Mild**: Unable to remember and understand recent events. Tasks such as cooking and driving become unsafe.
- **Moderate**: Unable to have conversations. Need full assistance with dressing and toileting.
- **Severe** : Unable to recognize loved ones. May be disruptive and yelling. Need help with all basic bodily functions.

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 fill out 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.

N Engl J Med 2017:2105

No Witness Requirements, Why?

- Witness requirement 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…

N Engl J Med 2017; 376:2105

- **<u>Legal framework</u>**: Dementia Directive can be a supplement to a Standard Advance Directive. (But OK as stand-alone also)

- **<u>Could it be notarized?</u>**

  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.
- Should never be a rigid algorithm.
- Their most important value:
- **Communicate** preferences to their loved ones.
- A tool to facilitate: *memorable* **conversations**
- With special bonus of: documentation!
  Something families can look back on later.

People 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 someone 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

- As dementia progresses: begin the conversation: "**if loved one could look on themselves now, what would they want?**"
- Mention the stress and potential harms of CPR, ER trips, and imaging tests.

the conversation project

WHAT MATTERS
CARING CONVERSATIONS ABOUT END OF LIFE

Institute *for* Healthcare Improvement

marlene meyerson JCC

Invaluable
POLST / MOLST

- **P**hysician **O**rders **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?

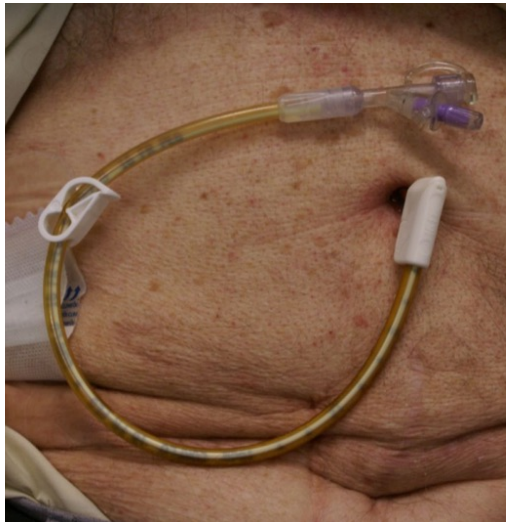
Remember the "Why"

- **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?"

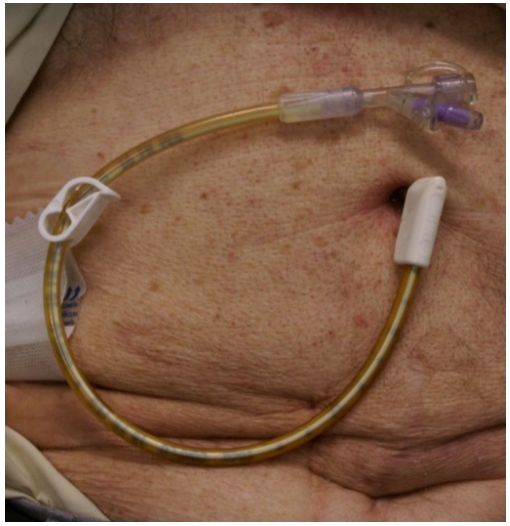
What About Tube Feeding?



- 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.

J Am Ger Soc. 2014:1590.

Tube Feeding Does Harm



- We may know this, but families often don't. 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…"

J Am Geriatr Soc. 2011;59(11):2009-16

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?"

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Dementia-directive.org