

Advance Care Planning for Dementia

Better Communication Better Care

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Why dementia's unique

- Slow, progressive, lose ability to understand.
- Lose capacity early to understand risks, benefits. Others make decisions on behalf. For many, many years.
- 80% of patients have prolonged phases of agitation. The typical course is rough.
- Many say they'd want gradual shift to comfort care. Navigating that shift is hard.

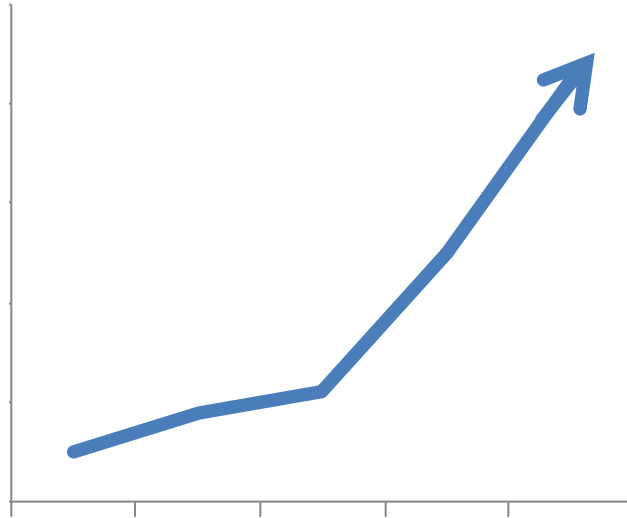
The Scope of Dementia



Over age 65:
1/10 have dementia.

Over age 85:
1/3 have dementia.

The Dementia Shock Ahead



Numbers to increase by 40% in next 10 years

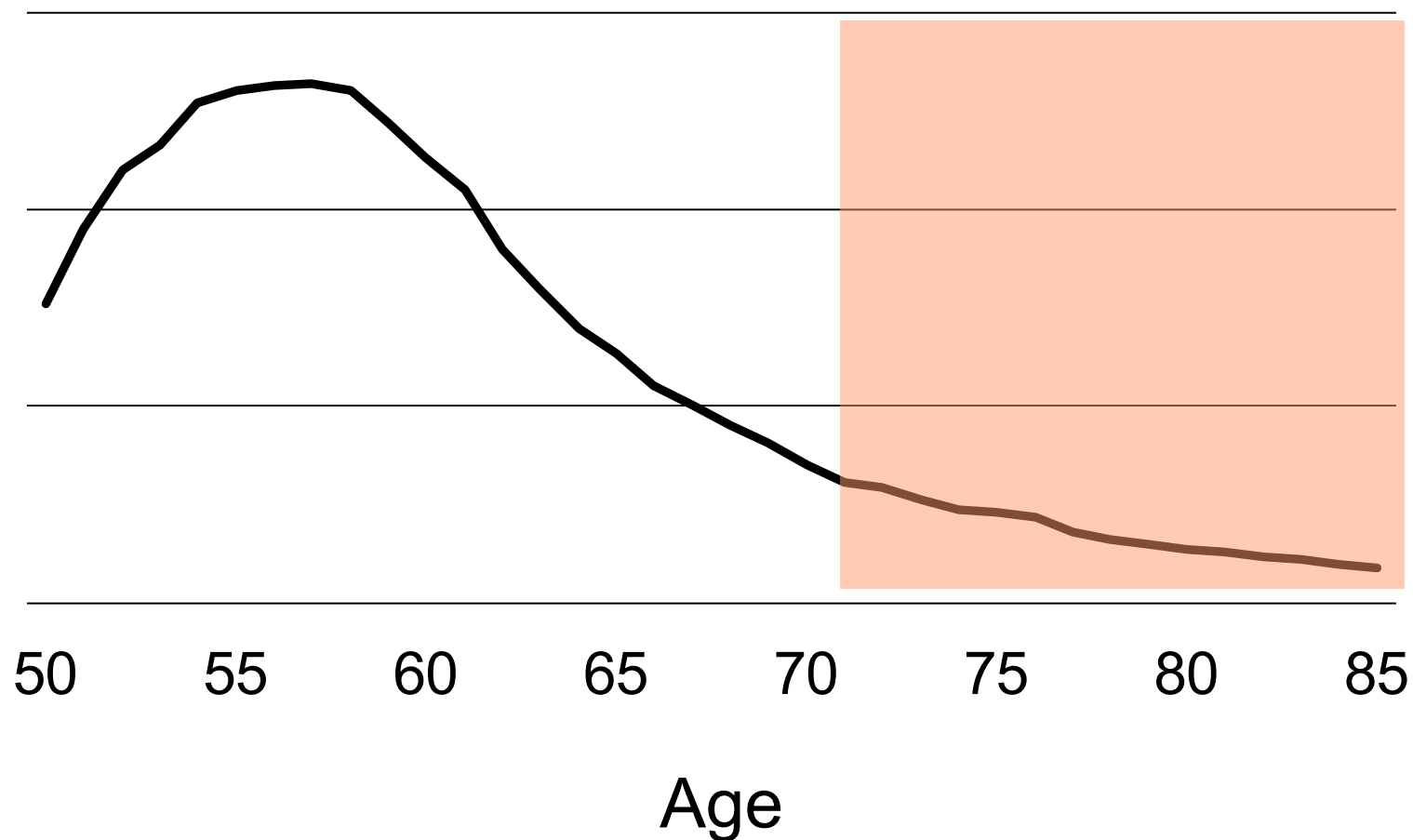
And will **triple** in the next 20 years ...

Baby Boomers Today

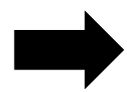


Today

Risk of Alz

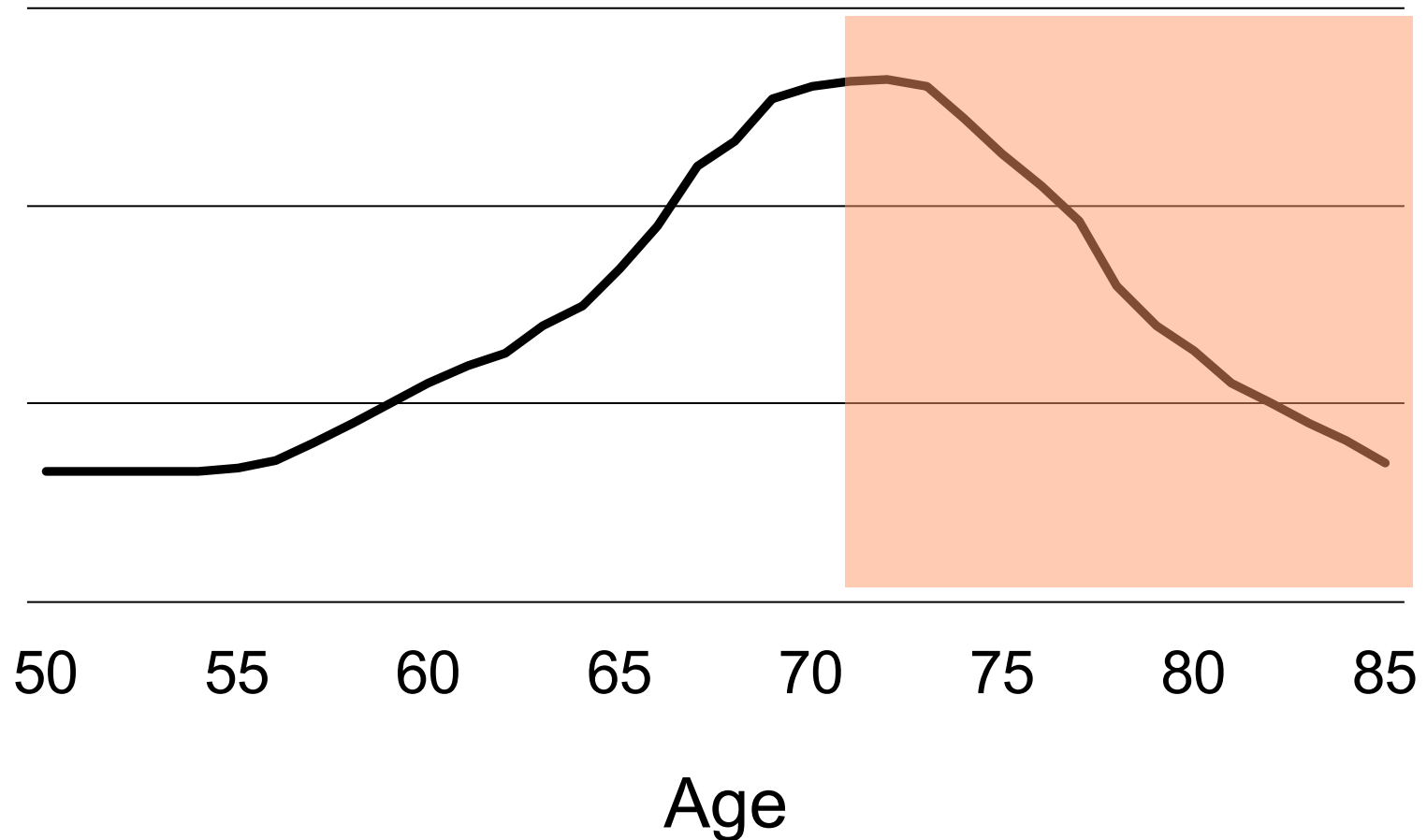


Baby Boomers 12 years from now



12 yrs from now

Risk of Alz



The #1 Disease Challenge We Face



Advance Care Planning for Dementia

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



- When our care aligns with values, preferences it's now recognized as higher quality care.
- Key to getting there: better communication.

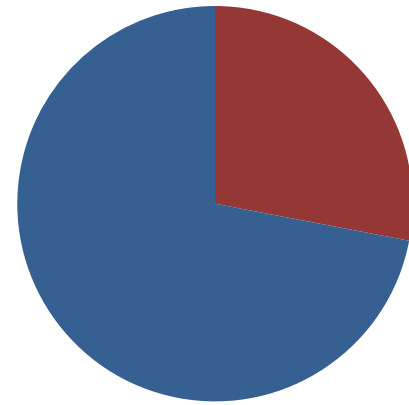


Many People Have Clear Ideas

Study: 200 people age 65+ no dementia



- Shown balanced depictions of living with dementia



- 72% indicated they would want comfort oriented care only

Standard Advance Directives

- Almost no guidance about dementia.
- Their focus: permanent coma or persistent vegetative state.
- Nothing that applies to the #1 reason people lose decision-making capacity (dementia)

..... Dementia is Complex

- Quality of life starts high then decreases: mild, to moderate, to severe stages.
- Most people would want different goals for their medical care, along those stages.
- People with early dementia still have years of tremendously good quality of life.

“I’m still here”



Dementia Directive

- Developed with input from experts in palliative care, neurology, geriatrics.
- Tested, refined in primary care setting.
- Available for free. Downloaded so far more than 130,000 times.

Dementia-directive.org

What If I Had Dementia?
Planning for the future

Mild

Moderate

Severe

Full code

DNR / DN Intubate

No ER or hospital

Comfort-oriented care

Care Options include “The Why”

- ☐ **Full efforts to prolong life:** including CPR.
- ☐ **No CPR, no intubation:** people with dementia who survive, at high risk much worsened state.
- ☐ **Avoid ER/hospitalization:** with dementia there is a high risk of adverse effects, complications.
- ☐ **Comfort-oriented care only:** focused on relief of suffering. Avoid antibiotics.

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!

Benefits of a Dementia Directive

- Peace of mind for those filling it out
- Peace of mind later for families
- Better care: Care which is more aligned with patients' values.

When to Consider a Dementia Directive?

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

www.dementia-directive.org

No Witness Requirements, Why?

- Witnesses might reduce the legal risk of challenge. But requirement creates a barrier to getting people to finish them.
- Fewer get done.
- Risk of conflict from people *not having* an AD is a greater risk than having one which is contested.

Advance Directives

- Advance directives are communication tools, general guidance for families. To communicate preferences and values. Not a rigid algorithm.
- Reasonable to think of the Dementia Directive as a supplement for people to attach to a Standard Health Directive.

In Early Dementia

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



Proxies (DPOA-H)

- Decisions by the proxy, at the point of care, are still what's most important.
- Early in dementia: So important for patients to designate, in a **legal form** their proxies. With alternates.
- Why? Over 20 years, their default may no longer be able to serve.

Guiding Advance Care Planning

When someone is already entering moderately severe dementia.



Having the Conversation

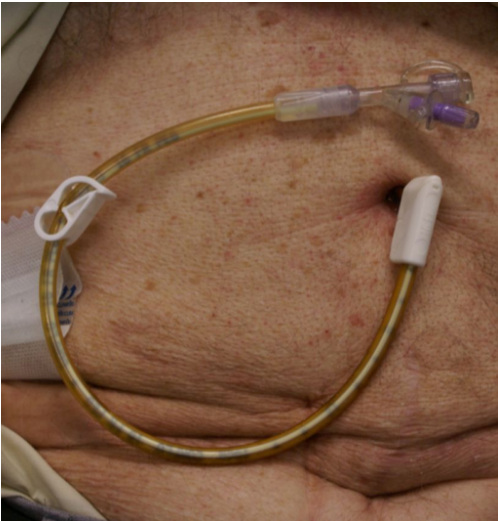
- Gentle communication: **if loved one could look down on themselves now, what would they say they'd want?**
- Take into account the stress, potential harms of CPR, ER's, invasive tests.

The Value of a POLST

The image shows a sample POLST form. It is a standard form used in the United States to document a patient's wishes regarding life-sustaining treatment. The form is titled "Physician Order for Life-Sustaining Treatment" and includes sections for patient information, physician information, and treatment preferences. It is a standard form used in the United States to document a patient's wishes regarding life-sustaining treatment.

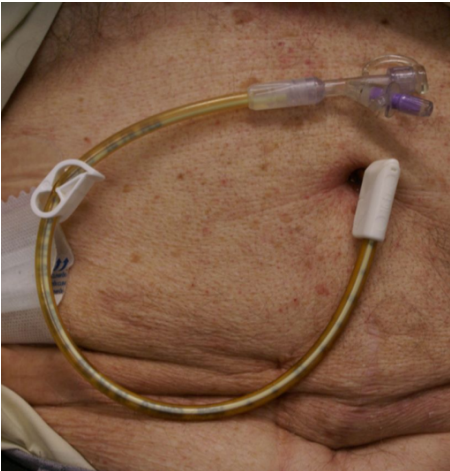
- **Physician Order Life Sustaining Treatment**
- A crucial tool to assist the conversation, to communicate with care teams.
- Sets goals of care **now**: What if heart stops. Or needs ventilator. Are we nearing time for comfort-oriented care?

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 in Directives?



- All acknowledge that this can be an emotionally hard decision.
- Needed: better conversations at bedside. We can't rely on eliciting preferences as an easy way out.
- Why? Doesn't make sense to ask if people would want an intervention which we know shortens life and would worsen their quality of life.

Billing for Advance Care Planning

- Since 2016 Medicare offers special payment premium for discussing ACP.
- Takes little added documentation. If you discuss ACP for > 15 minutes at an AWW the RVU's double from 1.5 to 3.0.
- As part of AWW, there is no added-cost to the patient (no copay, no deductible.)

Take Homes

- Early dementia: fill out a proxy-form DPOH (with *alternates*) ASAP in dementia.
- POLST. Valuable as dementia progresses.
- “Imagine if loved one could look down on themselves now, what would they say.”
- Offer the Dementia Directive to everyone once they reach age 65.

Let's Talk About Dementia

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