

# Advance Care Planning and Dementia

Path to better care

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# Why is dementia hard?

- Psychologically scary to consider.
- Tempting for (just about everyone!) to not face the possibility: could it be starting to happen now? or could it happen in future?
- But: we can **make care better** for our patients by talking about it, and by planning for it.

# 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 agitation, sometimes combative.
- Many would want a gradual shift to comfort-focused care. But when? How to decide?

# Advance Care Planning for Dementia

Helping align medical care people receive 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.**

# 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.
- It makes sense that people would want different goals for their medical care, from one stage to another.

“I’m still here”

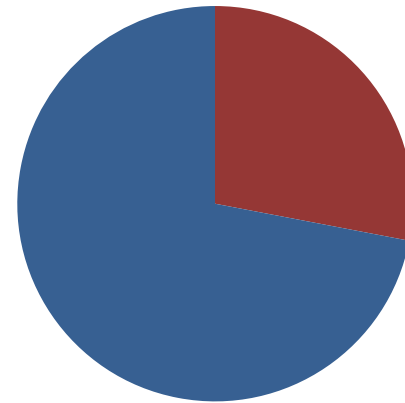


# Many People Have Clear Ideas

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](http://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

# 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” Someone Might Choose ...

- ❑ **No CPR, no intubation:** People with dementia, who survive, are at high risk of being in a worsened state if they survive. Someone might prefer to die more peacefully.
- ❑ **Comfort-focused care:** High risk of adverse effects, of agitation, more complications from many interventions. Someone might prefer fewer interventions.

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](http://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.

# People with Early Dementia

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



# In Early Impairment: Proxies (DPOA-HC)



- Early-on in the disease, it is 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

- Moderate/ severe stage: gently begin asking: **if (your loved one) could look on themselves now, what might they say they would have wanted?**
- Important to include considering the potential harms of tests and treatments.

the conversation project



# Invaluable POLST

**HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY**

Washington  
**POLST**  
Portable Orders for Life-Sustaining Treatment  
A Participating Program of National POLST

LAST NAME / FIRST NAME / MIDDLE NAME/INITIAL

DATE OF BIRTH / / GENDER (optional) PRONOUNS (optional)

**This is a medical order. It must be completed with a medical professional. Completing a POLST is always voluntary.**  
*IMPORTANT: See page 2 for complete instructions.*

MEDICAL CONDITIONS / INDIVIDUAL GOALS: AGENCY INFO / PHONE (if applicable)

**A** Use of Cardiopulmonary Resuscitation (CPR): **When the individual has NO pulse and is not breathing.**

CHECK ONE  YES – Attempt Resuscitation / CPR (choose FULL TREATMENT in Section B)  NO – Do Not Attempt Resuscitation (DNAR) / Allow Natural Death

*When not in cardiopulmonary arrest, go to Section B.*

**B** Level of Medical Interventions: **When the individual has a pulse and/or is breathing.**

CHECK ONE Any of these treatment levels may be paired with DNAR / Allow Natural Death above.

FULL TREATMENT – Primary goal is prolonging life by all medically effective means. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Includes care described below. Transfer to hospital if indicated. Includes intensive care.

SELECTIVE TREATMENT – Primary goal is treating medical conditions while avoiding invasive measures whenever

- **P**ortable **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.

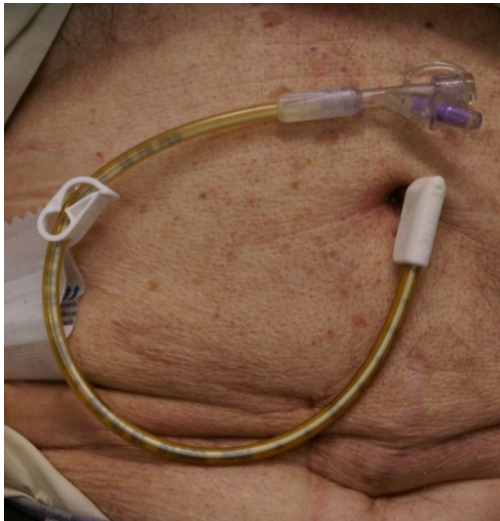
“Imagine if your loved one could look on themselves now, what might they say they’d want?”

# 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.

# Tube Feeding Does Harm



- People in health care may know this. But families usually don't. Key is to have this conversation in a caring and empathic way.
- Useful wording: “Tube feeding does not fix what is a slow dying process. It’s been shown to make people less comfortable.”  
“I worry the tube will *cause...*”

# What About Assisted Feeding?

## Before Tube Feeding



- Significant controversy. Is hand feeding “Basic care” or “medical care”? Many do feel strongly: that if they had severe dementia, then they would not want assisted feeding.
- Directives about this now available: EOLW and End of Life Choices NY.
- Can say: if very late-stage dementia: (I would) or (would not) want assisted oral drinking and eating.

# Key Points: Advance Care Planning and Dementia

- **Before dementia:** To everyone over age 65, offer a dementia directive: [Dementia-directive.org](http://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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