

AN ADVANCE DIRECTIVE FOR DEMENTIA

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PROBLEM SCOPE

5.5 million Americans have dementia

Over age 65: 10% have dementia

Over age 85: 32% have dementia

Alzheimer's Dementia 2017;13:325-373.

THE SHOCK AHEAD

Numbers to increase by
40% in next 10 years

Will triple in the next 20
years ...

Alzheimer's Dementia 2017;13:325-373.

The #1 Disease Challenge We Face



ADVANCE CARE PLANNING FOR DEMENTIA

Making sure that the medical interventions people get aligns with what they would have wanted.



DEMENTIA IS UNIQUE

- Unlike other common health conditions: many years in which patients are unable to make medical decisions for themselves.
- Families often unsure if decisions they make reflect what patients would have wanted.
- Source of tremendous distress for families. Wondering are we doing the right thing.

Annals Internal Med. 2011;154(5):336

MANY PEOPLE HAVE CLEAR IDEAS

- Study done in Boston: 200 people over age 65 without signs of dementia.
- Shown video or given verbal narrative of people with severe dementia.
- 72% indicated that they would not want any life-prolonging care in such a state (comfort oriented care only.)

BMJ. 2009;338:2159-67

DEMENTIA IS COMPLEX

- Quality of life gradually decreases as disease progresses from mild, moderate, to severe stages.
- Most people would want different goals for their medical care along these various stages.
- People with early dementia still have years of tremendously good quality of life.

STANDARD ADVANCE DIRECTIVES

- Standard AD's provide almost no guidance about dementia. Main focus is: permanent coma or persistent vegetative state.
- Yet: the #1 cause of losing decision making capacity is dementia.
- AD's not helpful here. Yet large number of people have clear ideas what they'd want.

JAMA. 2017;318(22):2175-2176

ADVANCE DIRECTIVE FOR DEMENTIA

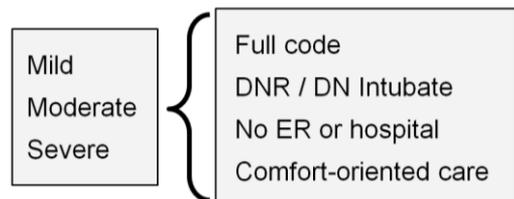
- Structured way for people, before they have dementia, to express their wishes.
- A communication tool to facilitate conversation and discussion.
- Allows for clear documentation: to be a resource to help inform the decisions which families might face in the future.

JAMA. 2017;318(22):2175-2176



Goal: improve the care we give by making sure it's aligned with the care that people would have wanted.

Dementia-directive.org



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!

IT DESCRIBES THE STAGES OF DEMENTIA

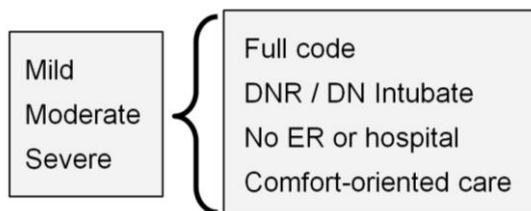
- **Mild:** Hard to remember recent events. Some tasks difficult / dangerous (cooking, driving.)
- **Moderate:** Communication very limited, need help with bathing and toileting.
- **Severe:** Unable to recognize loved ones. May be disruptive and yelling. Need around-the-clock assistance with every simple task.

IT DESCRIBES OPTIONS FOR GOALS OF CARE

- Full efforts to prolong life, including CPR.
- DNR and no intubation: allow peaceful death if cardiac or respiratory arrest.
- Avoid ER: provide antibiotics or other possible life prolonging treatments, if can be done in the home. But no hospitalization.
- Comfort-oriented caring care only, focused on relief of suffering. Avoid antibiotics.

www.dementia-directive.org

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BEST TIME FOR A DEMENTIA DIRECTIVE

Before signs of dementia occur.

Consider: for everyone at age
65-70.

www.dementia-directive.org

The Conversation Project

Your Conversation Starter Kit

For Families and Loved Ones of People
with Alzheimer's Disease or Other
Forms of Dementia

**Open ended guide for having
conversations about goals and
values with someone who
already has dementia.**

WHAT ABOUT TUBE FEEDING?



Feeding tubes in dementia do more
harm than good.

Strong expert guidelines, based on
good data-driven research.

Feeding tubes don't prolong life,
they cause more pneumonia,
they add to patient suffering.

J Am Geriatr Soc. 2014;62(8):1590-1593.

No sense in including an intervention known
to be harmful on a directive.

Question of FT's is often a complex and
difficult discussion with families.

But unwise to ask about a procedure on an
AD which we know does more harm than
good. We should avoid offering a care-
option for which there is wide consensus
that it's harmful, not beneficial, shouldn't be
offered.

J Am Geriatr Soc. 2014;62(8):1590-1593.

WHAT TO DO WITH A DEMENTIA DIRECTIVE

- Fill it out, think carefully about it.
- Review your answers with as many close family members as you can. Give them copies!
- Then mail a copy to your doctor also. Ask your doctor to review it and put it in your medical record. Discuss with him/her at your next doctor visit.

LEGAL AND CLINICAL CONSIDERATIONS

- We need to “delegalize” Advance Directives.
- A Living Will is primarily a guide for health care proxies to use, to inform them of patients wishes.
- Let’s take AD’s out of their security deposit box and into the doctor’s office, where they can better be used to guide care.

N Engl J Med 2017; 376:2105

- Requirements that AD’s be witnessed or notarized create a barrier to getting people to finish them.
- Fewer get done because of this.
- Rationale for witnesses: to prevent challenges. But there’s a higher risk of conflict from people *not having* AD’s at all than from AD’s which aren’t notarized.

N Engl J Med 2017; 376:2105

- So we left off an area for witnesses to sign a Dementia Directive in order to avoid this as barrier to completion.
- If someone wants to have it witnessed or notarized: certainly a good thing to do.
- But goal is to encourage as wide use as possible (as a written communication tool for health proxies to refer to.) Simple is better: improve care, reduce stress.
- Not legally binding. It’s there as a guide.

BENEFITS OF A DEMENTIA DIRECTIVE

- Peace of mind for those filling it out.
- Peace of mind later for families, knowing that the decisions they make on behalf of their loved ones are guided by what their loved one would have wanted.
- Better align care: by having a dementia directive available, it can help to inform our advance care planning discussions.

Dementia-directive.org



Care planning



Caring