Management of Dementia

Barak Gaster, MD, FACP
General Internal Medicine
University of Washington

Early Diagnosis -- Better Care

- Improve communication, support, get family involved.
- Align care, set goals of care, better care.
- Connect to community resources.
- Proven interventions that improve brain health: treat sleep apnea and hearing loss.

Overview for Today

Make a diagnosis of cognitive impairment

Set a plan for a newly diagnosed patient

Manage dementia as it progresses

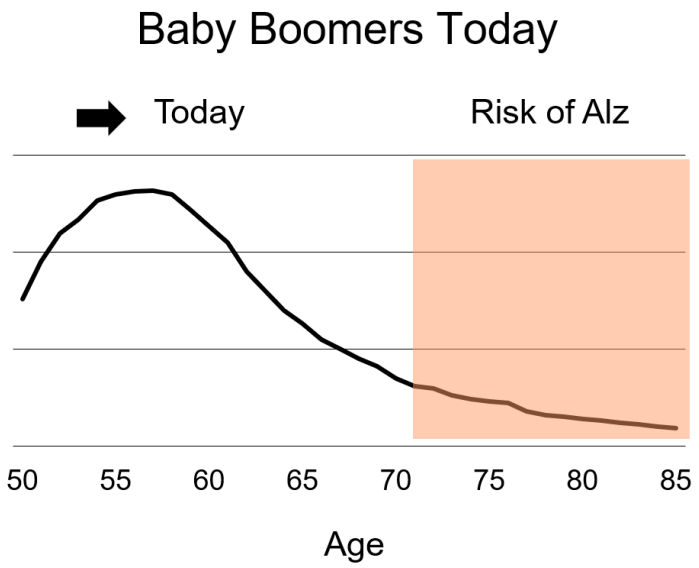
Dementia Shock Ahead

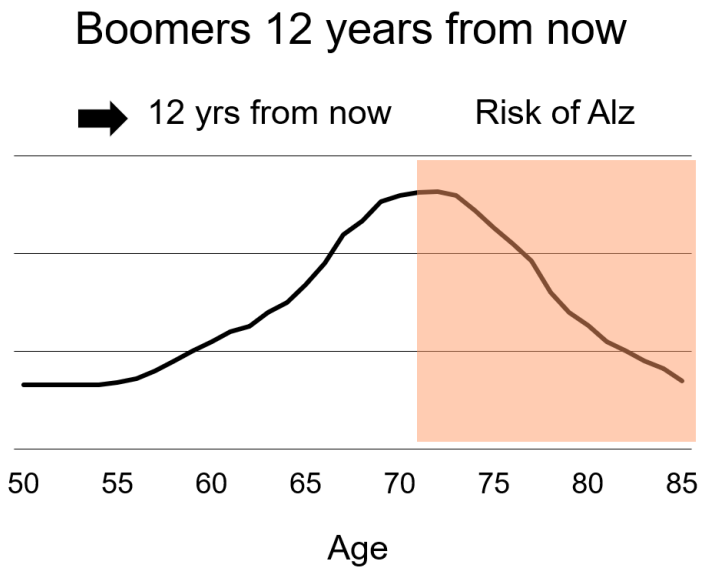
Now: 6.5 million Americans

35% of everyone over age 85

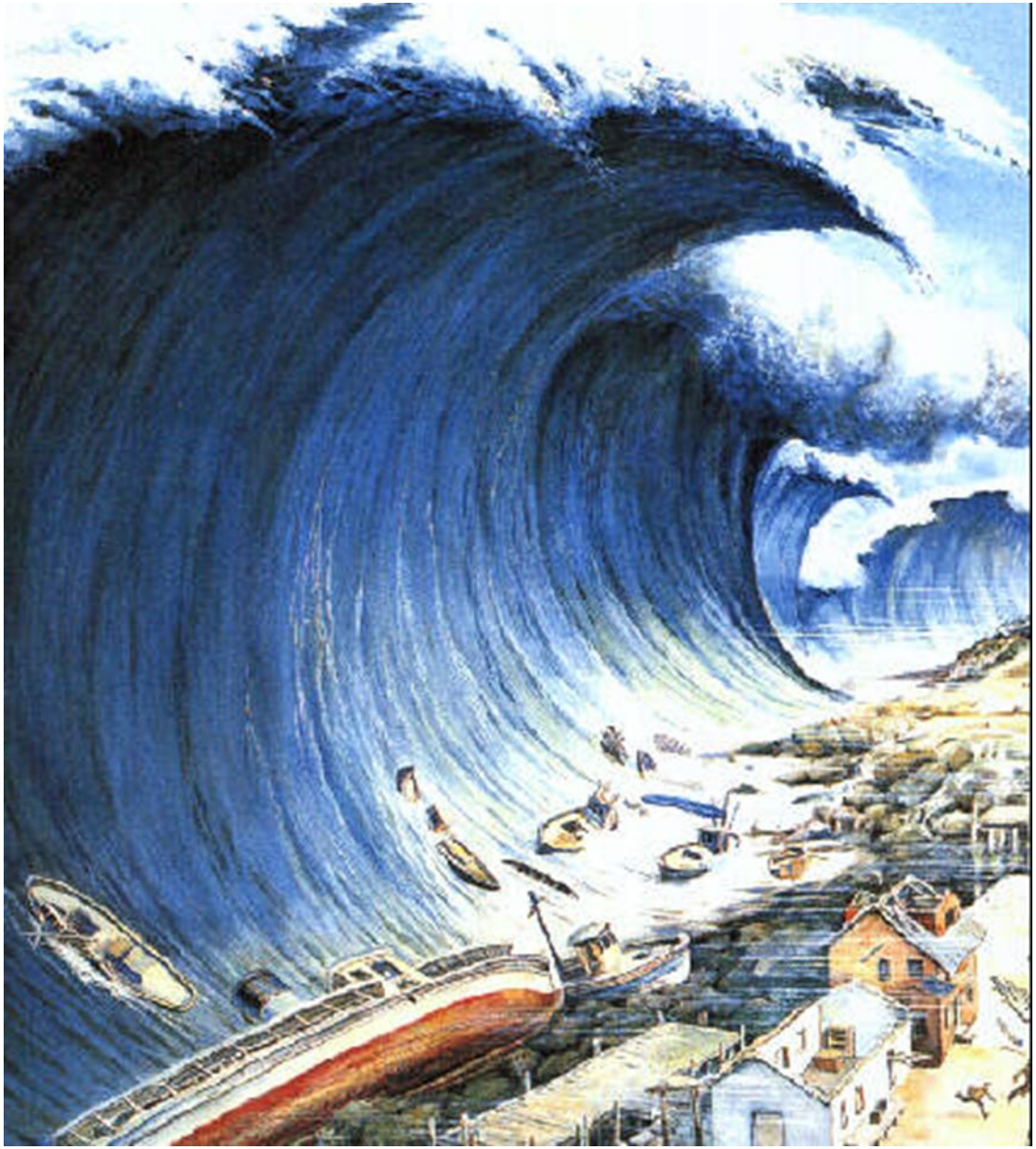
In the next 10 yrs: will ↑ 40%

Will **double** in the next 20 years





Alzheimer's Dementia 2022;18(4):700-789



Overview for Today

Make a diagnosis of cognitive impairment

Set a plan for a newly diagnosed patient

Manage dementia as it progresses

82 year old woman returns following a cognitive evaluation visit.

Husband has reported she's repeating the same questions and becoming disoriented in familiar surroundings.

Her MoCA score is 23/30.

Checklist for Newly Diagnosed

- ❑ Disclosure
- ❑ When to Refer to Neurology
- ❑ Brain Health
- ❑ Patient and Carepartner Support and Resources

Phrases for the newly diagnosed

"**Living with memory loss is not easy, but I will help you live well. We'll focus on brain health.** We will find ways to help you feel better, think more clearly, and find ways to still enjoy life."

"**You will not have to walk this path alone.** Your family, your friends, and me are with you as you move forward."

"**This is a lot to take in.** Let's see each other every 1-3 months until we have a good plan in place."

Living With Memory Loss. 2017. https://healthonline.washington.edu/

Checklist for Newly Diagnosed

- ❑ Disclosure
- ❑ When to Refer to Neurology
- ❑ Brain Health
- ❑ Patient and Carepartner Support and Resources

Who Needs Referral to Specialist?

- OK to hold off on a referral right away if there are no **red flags**.
- **Red Flags:** Atypical neurologic symptom, or

  Anyone before age < 65
- For many cases: it's OK to work up and follow, build trust with patient and family.
- But be aware of *visual* *hallucinations* …

Types of Dementia

Alzheimer's	**80%**	Memory loss is main symptom.
Vascular	**10%**	Almost always mixed with AD.
Lewy Body	**5%**	**Visual hallucinations.** Severe adverse reactions to antipsychotics. (Can cause severe Parkinsons.)
Frontotemporal	**5%**	**Very young onset** (most are below age 65.) Personality changes, such as apathy, severe mood swings.

Alzheimers Dement. 2021 Mar;17(3):327-406

Visual Hallucinations

- Raises question of Lewy Body Disease (LBD)
- LBD often a complex determination.
- Has major treatment implications (if LBD, much higher risk from antipsychotics.)
- Patients with visual hallucinations should be referred to see a specialist sooner.

Clin Geriatr Med. 2018 Nov;34(4):603-615

Checklist for Newly Diagnosed

- ❑ Disclosure
- ❑ When to Refer to Neurology
- ❑ Brain Health
- ❑ Patient and Carepartner Support and Resources

Brain Health

- **Alcohol (and drugs)**: Limiting 0-1 drinks will help.
- **Medications**: sedating and anticholinergic
- **Contributing Conditions**: Sleep apnea, hearing loss.
- **Exercise**: Daily brisk walks with a friend.
- **Cognitive Stimulation** Social engagement! (generally more useful than puzzles.)
- **Nutrition** Mediterranean-style diet good to recommend.

Checklist for Newly Diagnosed

- ❑ Disclosure
- ❑ When to Refer to Neurology
- ❑ Brain Health
- ❑ Patient and Carepartner Support and Resources

Powerful Tools for Caregivers

Free 6-week classes.
"Take care of yourself while
you take care of a loved one."

www.powerfultoolsforcaregivers.org

Making a diagnosis of cognitive impairment

Set a plan for the newly diagnosed patient

Manage dementia as it progresses

Donepezil or Memantine

- They do not change trajectory of disease.
- They do not work for early-stage impairment (MCI).
- Reasonable to *eventually* offer, as they are safe and easy to prescribe.
- **May** result in **small** improvements in some people. May slow loss of function a little.
- But *symptomatic* therapy, not neuroprotective.
- Higher priorities are hearing, sleep apnea, EtOH.

Annals Int Med. April 2020. PMID 32340037

Aducanumab

- Monoclonal antibody against amyloid plaque.
- FDA approved. But CMS-Medicare severely limited availability (only to patients enrolled in clinical trials, cost is > $30,000 per year.)
- Why? Because efficacy very controversial. Unclear if there's any clinical benefit. (Advisory panel to FDA voted 10-0 against approval.)
- Once monthly IV infusion, indefinitely. There is risk of brain edema/ bleeding.

JAMA. May 2021;325(17):1717-1718

Behavioral and Psychological Symptoms of Dementia

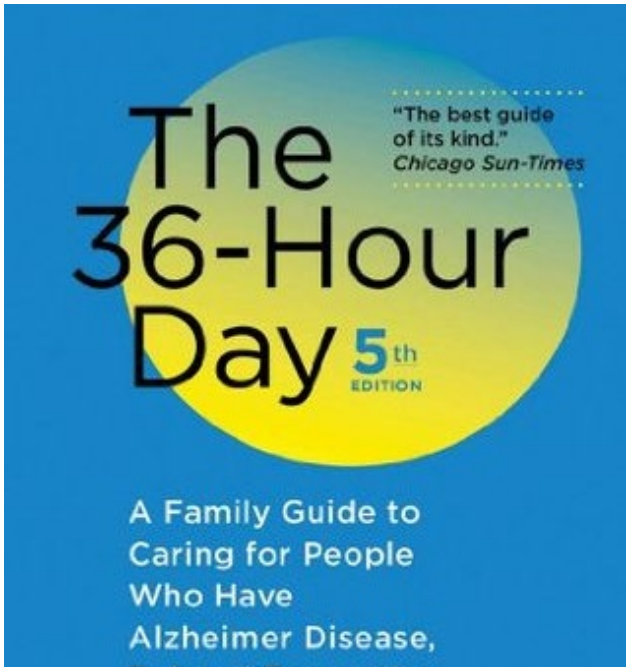
- The most troubling part of dementia.
- Agitation, paranoia, yelling, possibly hitting.
- Make sure: stopped oxybutynin, zolpidem.
- Benzodiazepines: often make symptoms worse. Use extreme caution.

Clinics Geriatric Medicine. 2020:36:2,329-39.

Non-Pharmacological Approaches

- Behavioral strategies really do help.
- Book for caregivers:
  "The 36-Hour Day."
- Website has handout with useful tips for communication

Cognition-PrimaryCare.org



Annals 2019 BMJ 2015

Talking to someone with dementia

- Talk directly to person, not about them (as if they weren't there.) They might not understand, but avoids distress.
- If person is agitated/ aggressive, stay calm. Perhaps withdraw. Don't be stern. Moment often passes.
- Meet people where they are. Avoid correcting to "bring back to reality." It causes distress, it doesn't help. Instead: change subject, engage in a related topic.
- Handout for families, covering this approach, is available on the website: Cognition-PrimaryCare.org

Learning to Speak Alzheimer's, Koenig-Coste (2003)

Antipsychotics: only if severe symptoms

- May be reasonable; but only if symptoms are severe and non-pharmacological approaches not enough. (Biggest concern using them is extreme sedation.)
- Start very low: Such as **quetiapine** 12.5 mg or **risperidone** 0.25 mg (once daily every evening.)
- Titrate up if needed every 3 days. Avoid using "as needed" (They don't work fast enough, ~ 2 hrs)
- Major pitfall: leaving them on too long. (Behaviors eventually improve.) Schedule taper off after 3 mos.
- Warning: Lewy body disease = severe Parkinsonism

Curr Psychiatry Rep. 2019 Jul 1;21(8):66

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**.

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

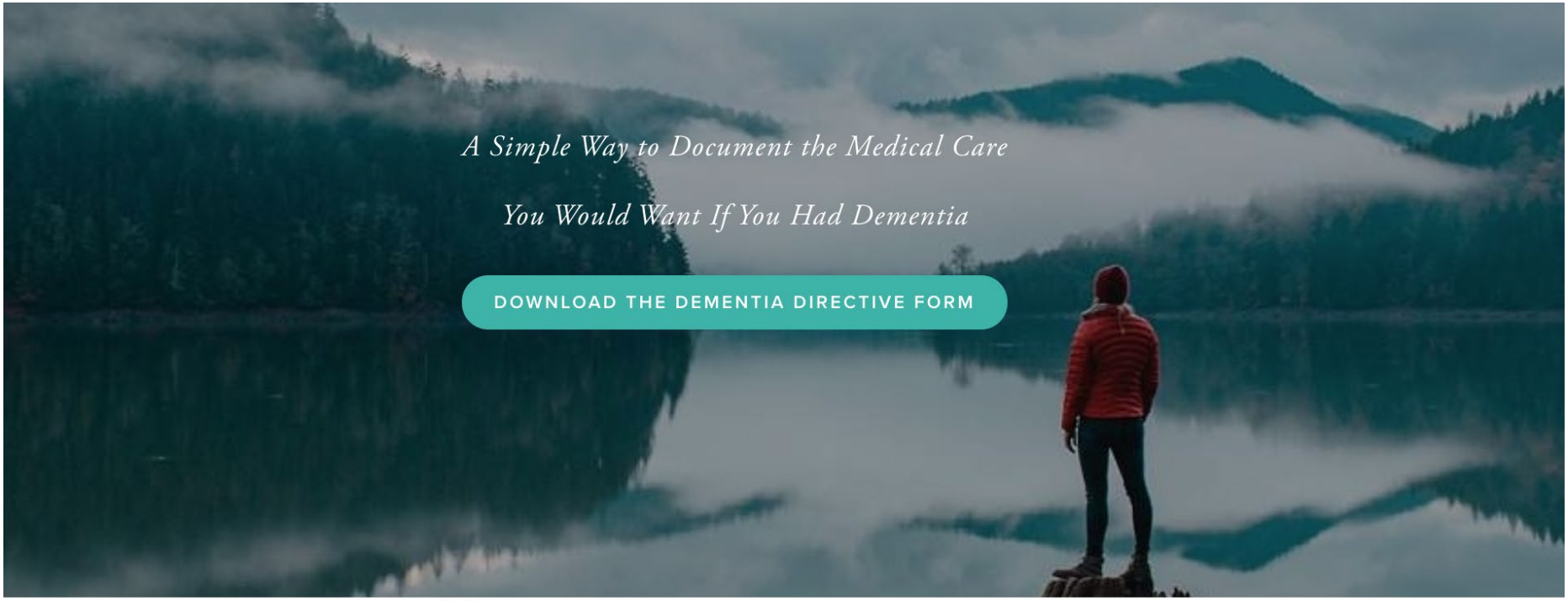
JAMA. 2017;318(22):2175–2176

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



INSTRUCTIONS | FAQS | RESOURCES | IN THE NEWS

An advance directive for dementia as featured in the New York Times.

DOWNLOAD THE DIRECTIVE

Best time to offer a Dementia Directive

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

www.dementia-directive.org

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.

The Invaluable POLST

- **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?"

The Medicare Annual Wellness Visit

- AWV still valuable, useful for patients with dementia.
- Useful to shift using AWV time to talk about Advance Care Planning.
- **Practice tip**: Use the easy-to-add billing code for Advance Care Planning to an AWV and double the RVU at no extra cost to the patient.

https://www.aafp.org/family-physician/practice-and-career/getting-paid/coding/advance-care-planning.html

Advance Care Planning billing code

- If you spend >15 minutes discussing advance care planning at an AWV – such as discussing dementia directive, DPOA, and/or POLST..
- Increases the RVU for the visit from **1.5** to **3.0**
- At no additional cost to the patient.

https://www.aafp.org/family-physician/practice-and-career/getting-paid/coding/advance-care-planning.html

Advance Care Planning billing code

Documentation for billing is very simple.

Simple wording, and which codes to use, are on a 1-page easy handout:

www.Cognition-PrimaryCare.org

https://www.aafp.org/family-physician/practice-and-career/getting-paid/coding/advance-care-planning.html

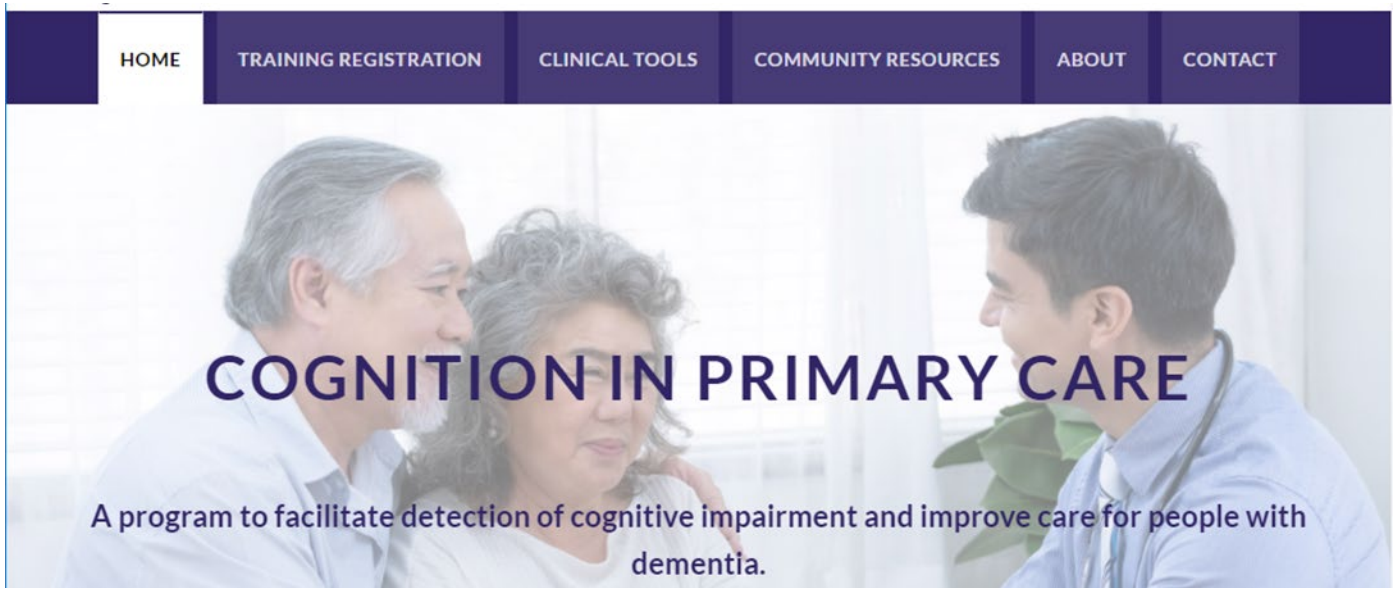
Key Points

- Donepezil or memantine safe, easy to offer, but small benefit. **Not** effective for people with MCI.
- Behavioral symptoms should be treated with non-pharm approaches. Use antipsychotics only when symptoms are **severe** and non-pharm fails.
- If Lewy Body Disease, remember the major caution with using antipsychotics (severe Parkinsonism.)

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?"

Q+A

Download Free Summary Tools!

Cognition-PrimaryCare.org