

Dementia and Primary Care

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Why is dementia hard?

- The diagnosis in early stages is often tricky.
- Tempting for patients and PCPs to skip over it.
- **But**: we can intervene meaningfully if we identify it early!

Early Diagnosis Leads to Better Care

- We can provide more appropriate medical care:
 - reconsider pros/ cons of some preventive care
 - modify communication styles
 - align decision making with goals
- We can increase support & understanding, major impact when we involve and educate families.
- Make connections earlier to community resources.

continued

Better Care

- Improve patient safety: driving, finances, home.
- Limit medications that harm cognition.
- Treat contributing conditions (eg hearing, sleep apnea)
- Advance care planning: major value when we are able to set up a DPOA - with alternates - while patient is still able to identify who they would trust most.

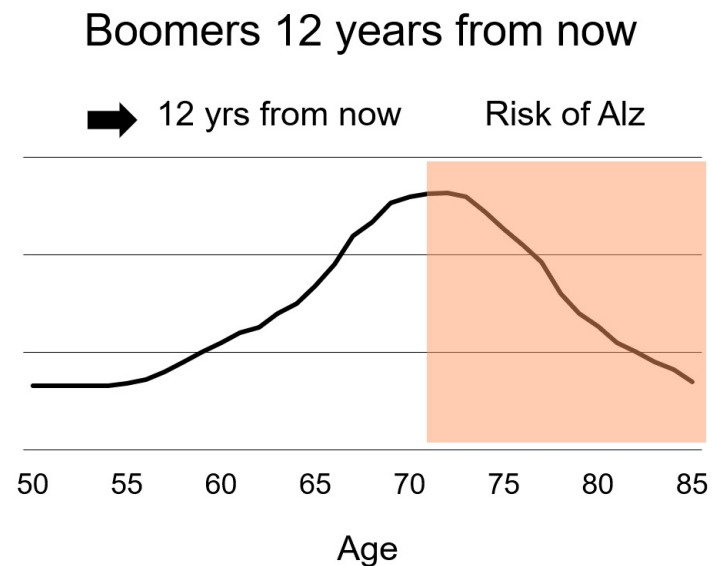
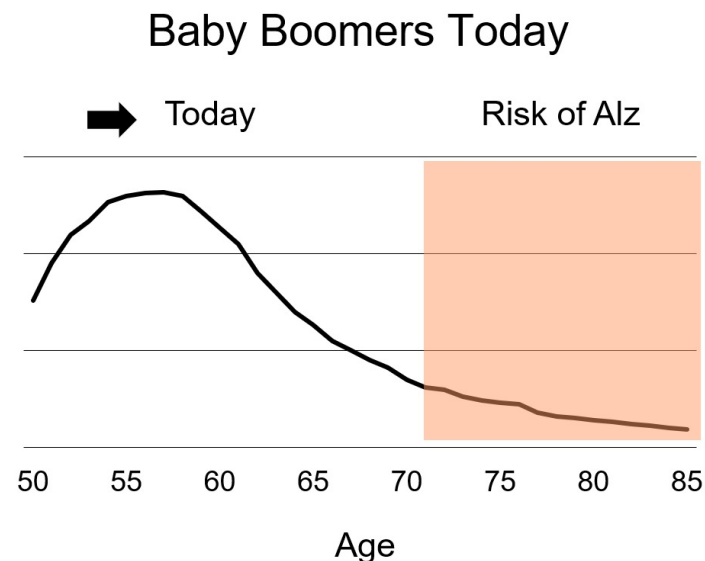
Dementia Shock Ahead

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





Roadmap Today

Make a diagnosis of
cognitive impairment

Set a plan for a newly
diagnosed patient

Manage dementia as
it progresses

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Evaluating Cognition in Primary Care

- Perform a cognitive evaluation.
- Identify reversible and contributing causes of cognitive impairment you can fix.
- Distinguish “Mild Cognitive Impairment” from Dementia

Be Aware: three situations...

- Patient or family mention a concern.
- On Annual Wellness Visit questionnaire: needs to be some kind of question about memory concerns: Patient answers “yes.”
- Anyone in clinic (front desk, MA, PCP, etc) notices confusion about appointments or medications.

Decide: Questions that help decide who needs a cognitive assessment

Normal aging vs worrisome signs

Normal: Longer to remember names or misplacing keys

Abnormal: Forget things that just happened?

Such as: repeating same story/ question 30 minutes later.

Abnormal: Hard to do complex task that used to be easy?

Example: Trouble w. complex recipe, organizing documents.

Abnormal: Unsure where you are, in place been to often?

Example: disoriented in a building one should know well.

Warning Signs Aid

- A one-pager, with 3 questions
Medical Assistant or PCP can give

Worrisome Signs vs. Normal Aging

- Adapted from “10 Warning Signs”
document from Alzheimers Assoc
- Download for free from

Cognition-PrimaryCare.org



Cognition in
Primary Care

Version: 9/2/2021

Follow-up Questions About Cognitive Concerns

1. Have you noticed that you forget things that just happened more often?
For example: Repeating the same question or the same story 30 minutes later.

YES

NO

UNSURE

2. Have you noticed it's more difficult to finish a complex task that used to be easy
for you?
For example: Cooking a complex recipe, organizing your documents, or putting up
outdoor holiday lights.

YES

NO

UNSURE

3. Have you noticed being unsure where you are in a place you've been to many
times?
For example: Becoming disoriented on a usual route or in a building you know
well.

YES

NO

UNSURE

Note: The following changes are normal as people age. They are less a cause for concern:

1. Forgetting the name of someone but remembering it later.
2. Noticing it takes longer to come up with a word you're trying to remember.
3. Misplacing keys or forgetting why you went upstairs, but later you find your keys or remember why you went upstairs.



Cognition in Primary Care

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COGNITION IN PRIMARY CARE

A program to facilitate detection of cognitive impairment and improve care for people with dementia.

Decide: Based on this questioning

- Should a dedicated visit for a full cognitive evaluation be very strongly encouraged?
- If so, try very hard to get a family member to come.
- Eval works much better as a longer visit, if possible.
- Huge change: longer **Level 5** visits are now double RVUs than Level 3. (this went way up in 2021)
- Level 5 is 40 minutes total spent on care (both prep and charting) ... not just face-time.

Dedicated Visit to Evaluate Cognition Concerns – what to do

1. Checklist: reversible causes and other factors you can fix.
2. Assess cognitive function with MoCA.
3. Also get input from family or friend.

“Cognitive Checklist”

- B12 and thyroid**
- Med list** sedating/ anticholinergic meds?
e.g. oxybutynin, Tylenol PM, benzos, zolpidem
- Alcohol** - Even mild-to-moderate drinking can impair cognition once people > age 70
- Other:** Sleep apnea, hearing loss, depression

Evaluating Cognitive Function

- We as PCP's should be comfortable evaluating cognitive function.

The assessment is a combination of...

Family input

+

a 10-min cognitive test

RVU for Level 5 (2021) went up 33%! Double Level 3

Family Observer Input

- Key questions to ask a family observer:
 - Repeating the same question 30 min later?
 - Losing ability to do complex tasks that person once found easy? (e.g. outdoor lighting or complex recipe)
 - Getting disoriented in familiar places?
- Get used to asking these 3 questions (or use Decision Aid)
- Or use the fully validated 8-item form: **the AD8**

Both forms available at: **Cognition-PrimaryCare.org**



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AD8

Or asking
3 questions
at bottom of
checklist to
get quick
input from
family

Remember, "Yes, a change" indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.	YES, A change	NO, No change	N/A, Don't know
1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)			
2. Less interest in hobbies/activities			
3. Repeats the same things over and over (questions, stories, or statements)			
4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)			
5. Forgets correct month or year			
6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)			
7. Trouble remembering appointments			
8. Daily problems with thinking and/or memory			

MoCA Montreal Cognitive Assessment

- More sensitive than MMSE ... and no \$2 fee
- By far best validated tool to assess early cognitive impairment in primary care setting.
 - ≥ 26 Cognitive impairment less likely.
 - 20-25 Uncertain. Incorporate family input, follow.
Offer neuropsych evaluation.
 - < 20 Dementia very likely.

Putting It Together

Family input

+

MoCA result

Say person's MoCA is less than 20.

+ Family notes gradual changes over time

+ Family reports difficulty with activities daily living

= dementia.

Putting It Together

Family input

+

MoCA result

Say person's MoCA is between 22-26

+ Family notes cog changes beyond normal aging

+ But still able to dress and cook and clean house

= mild cognitive impairment

What is Mild Cognitive Impairment?

- If MoCA is 24-26 and family reports cognitive changes. But activities daily living intact => MCI
- Whereas for dementia: MoCA is often lower <24 and patient losing independence with activities.
- Note: a large majority of patients with MCI progress to dementia (70%.) But 30% with MCI don't progress.
- Most with MCI do have early Alzheimer's (not all)
- Action! Focus on brain health: (EtOH, hearing, sleep apnea.) Fill out DPOA form. Repeat eval yearly.

At end of evaluation: set up next visit

- **If evaluation looks OK**, discuss ways to keep brain healthy (minimize alcohol, regular exercise, make sure to treat hearing loss.)
- **If diagnosis is mild cognitive impairment or dementia**, say: “This is a lot to take in and work through. Let’s schedule another visit in 2-3 weeks to review what this means and make a plan.”
- Strongly consider another longer (Level 5) appt. Again encourage family to attend. Caution: ~~diagnose and adios.~~

Key points

- We can do cognitive evaluations in primary care. Tools at Cognition-PrimaryCare.org
- Getting family input (if at all possible) is an essential part of the evaluation.
- Combine the MoCA and the family input to make an assessment.
- Address brain health and key modifiable causes of mild cognitive impairment: Alcohol, sleep apnea, hearing loss, and medications.

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cognitive impairment

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Diagnosis Discussion Checklist

- Disclosure and Prognosis**
- When to Refer to a Specialist**
- Brain Health**
- Patient and Caregiver Support and Resources**
- Follow-up**

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Disclose the Diagnosis

Delivering Bad News

- Try to have family there.
- Set the Stage: Ask first: **“Is it OK if I share what I think is going on?”** This preps them for bad news. In effect, you’re asking “are you ready now?”
- Acknowledge fear. But also share hope, some optimism. **“This is good to know, it will help to be more ready.”**
- Give ongoing support. Set up next meeting in 1-2 mos. Invite additional family to attend.

Disclose the Diagnosis

What Terms to Use

Should we say “Mild Cognitive Impairment” or “Early Alzheimer’s”?

- Many people have never heard of “Mild Cognitive Impairment.”
- Don’t falsely reassure (“Phew, thank goodness it’s not Alzheimers!”)
- But also don’t scare people too much. If it’s MCI: there’s a 30% chance that over the next 6-8 years it may not progress.
- Say: “I’m worried you might have a high chance of **early Alzheimer's**. Let’s watch things closely.”
- And: “Let’s look at changes to make for brain health. There are ways we can help. If this does get worse, it happens very slowly.”

Talking Prognosis

- If it's MCI: "there's a 30% chance that 6-8 years from now you could be exactly the same."
- If it's dementia: timeline to progression is very slow. Also timeline hard to predict: 6? 10? 12? 15? yrs
Reassure: "You'll be very near to where you are now for years to come."
- Give support: "I'll be here with you. We're hoping for best. But I'm here to help if things get worse. It's so good to have family here with us to help."

Phrases to use 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.”

Diagnosis Discussion Checklist

Disclosure and Prognosis

When to Refer to Specialist

Brain Health

Patient and Caregiver Support and Resources

Follow-up

Who Needs a Referral?

- It should be a shared decision with patients.
- It's OK to hold off on a referral if no red flags.
(atypical neurologic symptoms or age < 65)
- For many cases: it's OK to work up and follow,
build trust with patient and family.
- But be aware of atypical dementia symptoms...

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.

Visual Hallucinations

- Raises question of Lewy Body Disease (LBD)
- LBD often a complex determination.
- Has major treatment implications (those with LBD have higher risk from antipsychotics.)
- Patients with visual hallucinations should be referred to a Neurologist or other specialist.
- Ask about Visual Hallucinations on checklist.

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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.)

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Referrals for Support

- Reinforce that life continues for potentially many good years down the road. It's possible to live well with memory loss.
- Alzheimer's Association Website: Local Resources



Powerful Tools for Caregivers

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



www.powerfultoolsforcaregivers.org

Key Points

- Even if diagnosis is mild cognitive impairment, mention high concern for Alzheimer's disease.
- But include optimism. With support, people can live well with dementia. If Mild Cognitive Impairment, include that there is prognostic uncertainty.
- If visual hallucinations, then refer to a Specialist (possible Lewy Body Disease.)
- Provide resources. Make a clear follow-up plan.

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cognitive impairment

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progresses**

Medications to treat dementia

- It's reasonable to offer a trial of donepezil.
- It may result in small improvements in cognition and function. May slow loss a little.
- Symptomatic therapy, not neuroprotective.
- It does not change trajectory of disease.
- It does not work for early-stage memory loss (MCI).

Aducanumab

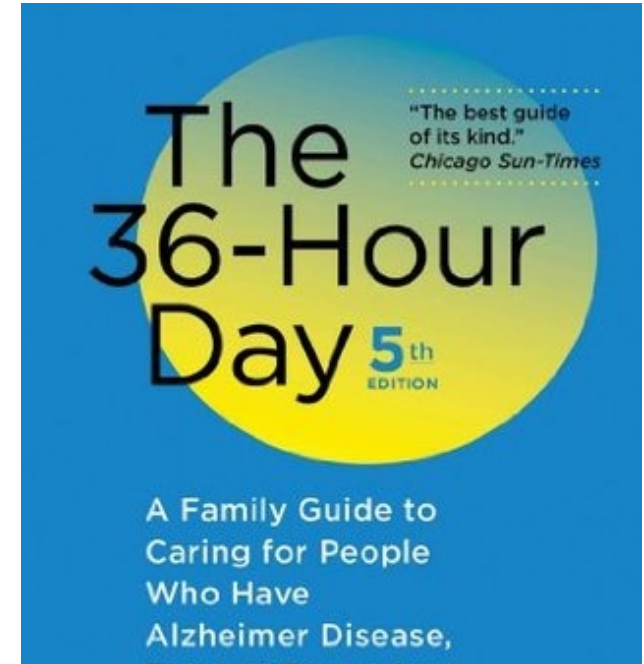
- Monoclonal antibody against amyloid plaque.
- Efficacy controversial.
- FDA approved. But severe payment restrictions set by CMS-Medicare (patients must be enrolled in a trial)
- Given indefinitely as a once per month IV infusion, some risk of brain edema/ bleeding.
- Next week's session: Dr. Grabowski will be reviewing aducanumab and other possible new therapies which might be coming down the pike.

Behavioral and Psychological Symptoms of Dementia

- The most troubling part of dementia.
- Agitation, paranoia, yelling, possibly hitting.
- Up to 80% of patients with dementia develop such symptoms at some point in the disease.
- Make sure: stopped oxybutynin, zolpidem.
- Benzodiazepines: often make symptoms worse. Use extreme caution.

Non-Pharmacological Approaches

- Behavioral strategies really do help.
- Book for caregivers:
“The 36-Hour Day.”
- Alzheimer's Association
- Powerful Tools For
Caregiver's Program
- Tips for communication...



Talking to someone with dementia

- Talk directly to person, not about them (as if they weren't there.) Even if they don't understand, it avoids distress.
- If patients are agitated/ aggressive, remain calm. Maybe withdraw. Don't be stern. The moment often quickly pass.
- Use music or art to bring simple joy to every day.
- Meet people in the reality where they are. Avoid correcting to try "re-grounding." Causes distress and doesn't help. Instead: change the subject, engage in a related topic.
- Handout for families covering this approach is available on our website: Cognition-PrimaryCare.org

Antipsychotics: only if severe symptoms

- May be reasonable; but only if symptoms are severe and non-pharmacological approaches not enough. (Biggest concern from them is extreme sedation.)
- Start very low: Such as **quetiapine** 12.5 mg or **risperidone** 0.25 mg (once daily in evening.)
- Titrate up if needed every 3 days. Avoid using “as needed” dosing (at 1-2 hrs, don’t work fast enough.)
- Major pitfall: leaving them on too long. (Behaviors eventually improve.) Schedule taper off after 3 mos.
- Warning: Lewy body disease = severe reactions

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 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.

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



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

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



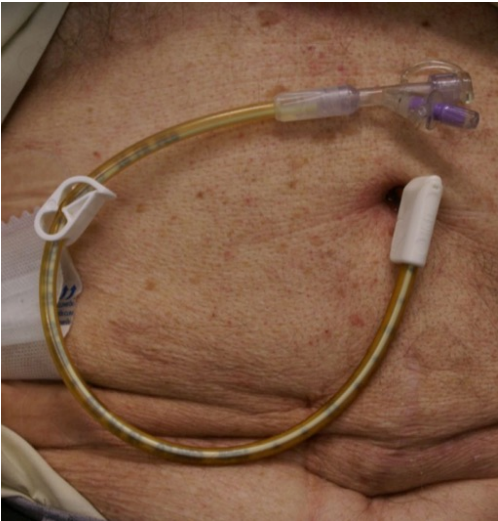
- **P**ortable **O**rder **L**ife **S**ustaining **T**reatment
- A crucial tool: anchors GOC conversation. Invaluable communication across sites.
- Sets goals of care **now**: What if heart stops. Or can't breathe on own. Is the preference for: comfort care? ICU care?

Remember the “Why”

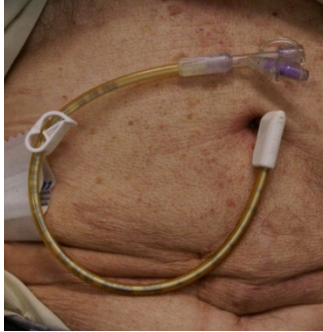
- ❑ **No CPR, no intubation:** Why might choose: people with dementia who survive, are at high risk of being in a worsened state if they survive.
- ❑ **Comfort-focused care:** symptom relief only.
Why: high risk of adverse effects, of agitation, more complications from many interventions.

“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.
- Based on solid data research, strong expert guidelines.
- They don't make people more comfortable, don't prolong life, they cause more aspiration pneumonia, more suffering.



- Explain: weight loss is a difficult, unavoidable part of late-stage dementia. We can adjust feeding to keep people comfortable, but there is no treatment to reverse it.
- “Feeding tubes don’t fix the slow process, of dying from dementia. I worry it would very likely make your mom/dad less comfortable. Feeding tubes actually increase suffering. They really do hurt more than they help.”

Key Points

- Donepezil is easy to use, so offer it, but generally very small benefit. And not effective for MCI.
- Behavioral/ psych symptoms should be treated with non-pharm approaches. Use antipsychotics only when symptoms are severe and non-pharm fails.
- If Lewy Body Dz, major caution using antipsychotics.
- Don't use antipsychotics "as needed." Schedule them. Titrate up every 3 days. Schedule taper to off.

Advance Care Planning - Takeaways

- **Dementia Directive:** offer to everyone over age 65, before dementia. Also may use ACP code at AWWs.
- **Mild dementia:** fill out a DPOA-HC proxy document (with alternates) as soon as possible.
- **Mod/severe dementia:** POLST is appropriate, valuable
- **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