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# Dementia Care Through Every Stage

*10 ways to nurture compassionate, dignified,  
individualized care*





This is all of us

“Aging is a team sport.  
If you’re playing alone,  
you’re going to lose.”

Bill Thomas, MD, Co-founder of the Eden Alternative



Interdependence

Is dementia one thing or many?

How does it change over time?

# What Can I do to Prevent Dementia?

SLEEP is the #1 controllable risk factor (that we ignore!)

- read “Why We Sleep” by Dr. Matthew Walker – it will change your life

EXERCISE DAILY – OUTSIDE IF POSSIBLE

EAT MOSTLY PLANTS – TO FUEL THE GUT/BRAIN HIGHWAY

TAKE AS FEW MEDICATIONS AS POSSIBLE

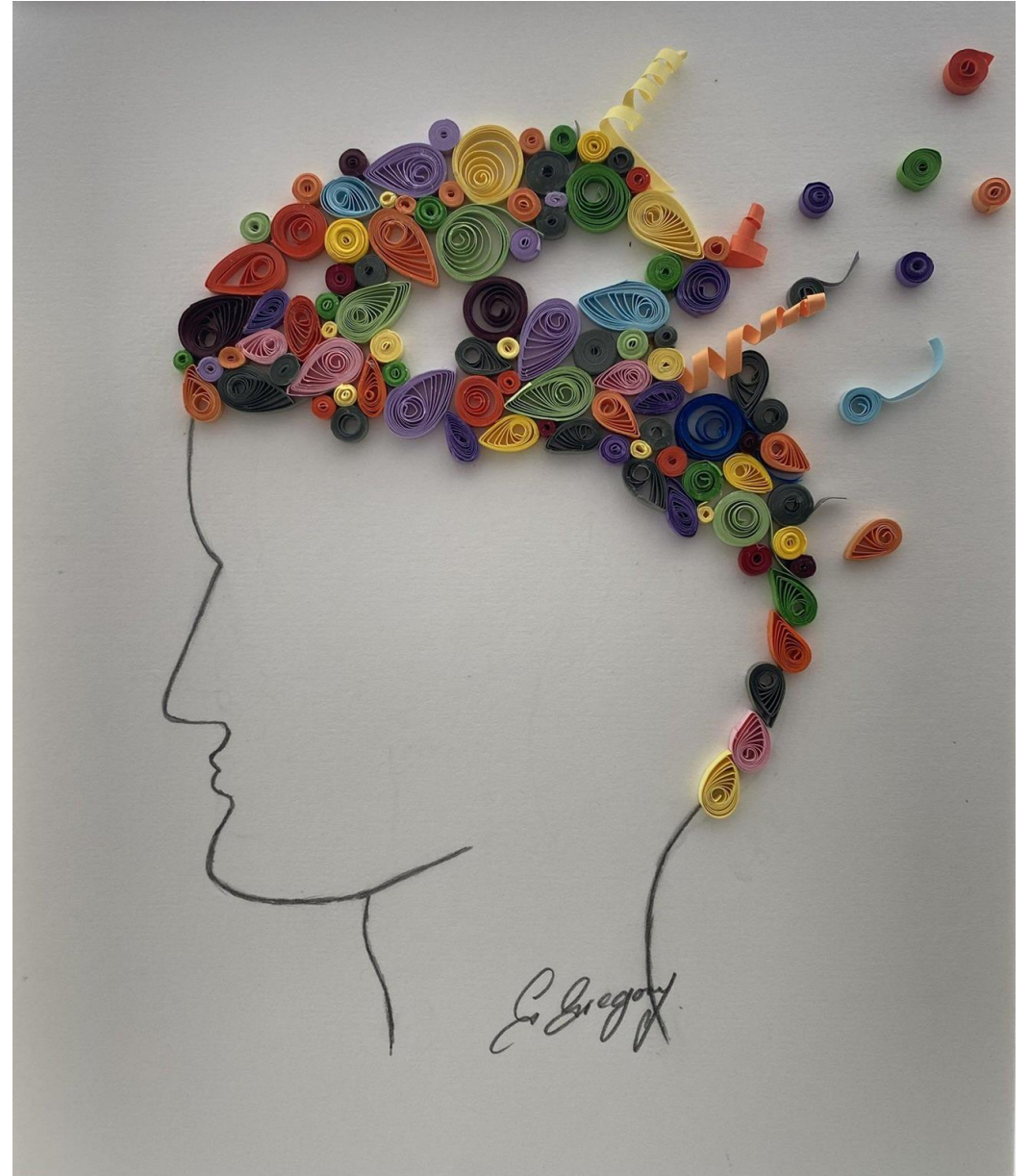
CONNECT WITH OTHER LIVING BEINGS

People with mild – moderate dementia can lead fulfilling lives.

The biggest barriers are ageism and limited access to affordable resources.

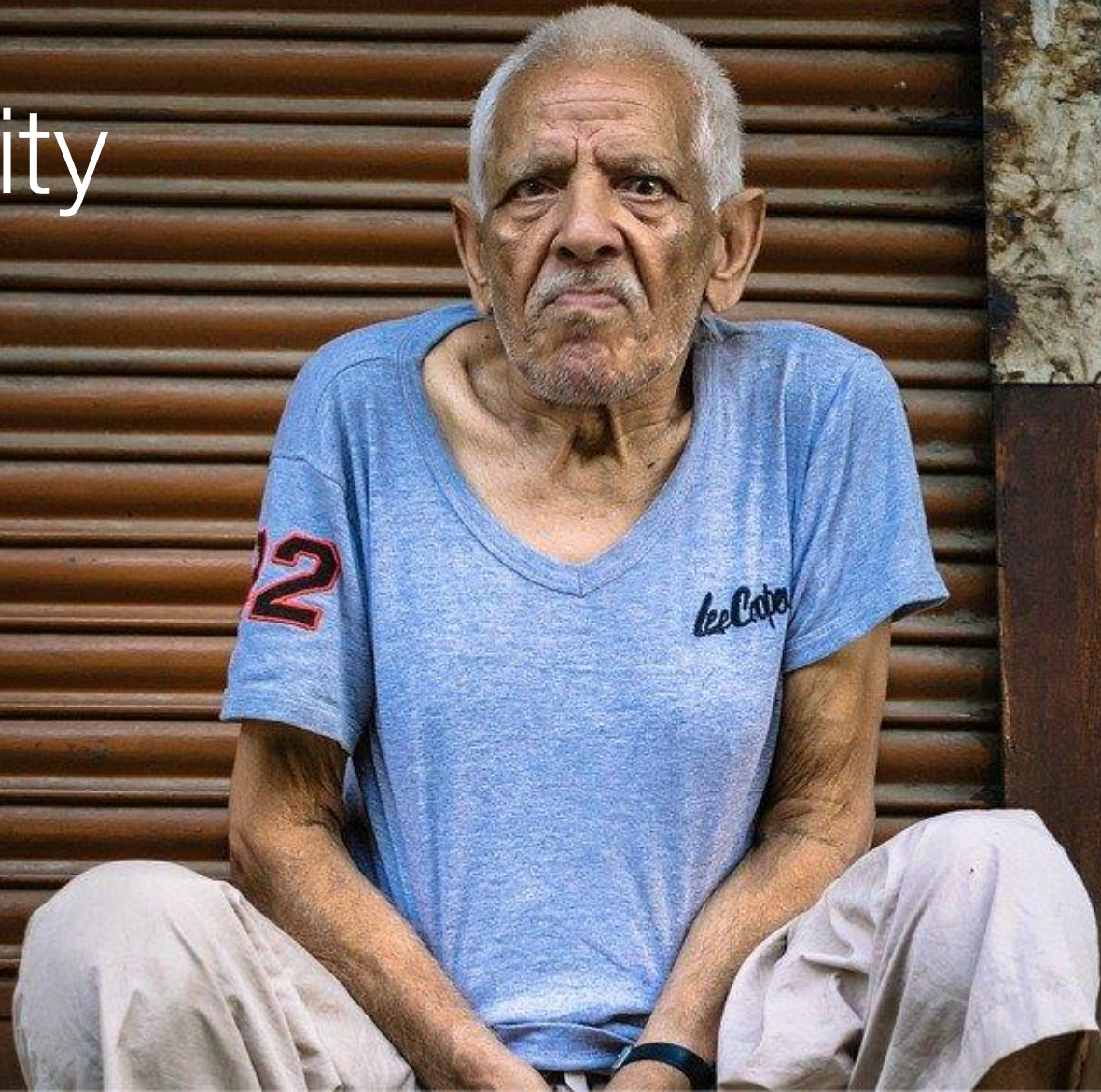
# “Dementia Inside My Head”

by Gail Gregory  
(living with dementia)





Dignity







Unique

# Unmet needs

- Boredom
- Comfort: pain, hunger, thirst, constipation, fatigue, touch
- Response to change in environment
- Acute medical illness (is the change sudden?)
- Medication side effects/interactions
- ***Is the patient declining in general? Is it time for a more structured environment? to revisit goals of care?***

# Bad for dementia (and everyone else...)

Loud, artificially  
bright, limited  
privacy

Crowded,  
chaotic  
mealtimes

Inflexible  
activities and  
times

No  
spontaneous  
access to  
outdoors

High staff  
turnover,  
inconsistent  
care





Control

"ALLOW WHEN YOU CAN, PROTECT WHEN YOUR MUST"

# Alzheimer's Communication

1. Never **Argue.**  
Instead **Agree.**

2. Never **Reason.**  
Instead **Divert.**

3. Never **Shame.**  
Instead **Distract.**

4. Never **Lecture.**  
Instead **Reassure.**

5. Never say  
"**Remember.**"  
Instead **Reminisce.**

6. Never say "**I Told You.**"  
Instead **Repeat.**

7. Never say "**You Can't.**"  
Instead say what they  
**Can Do.**

8. Never **Demand.**  
Instead **Ask.**

9. Never **Condescend.**  
Instead **Encourage.**

10. Never **Force.**  
Instead **Reinforce.**





There are many doors to success.  
Keep trying until you find the right one.





Purpose





Americans are on too many medications.

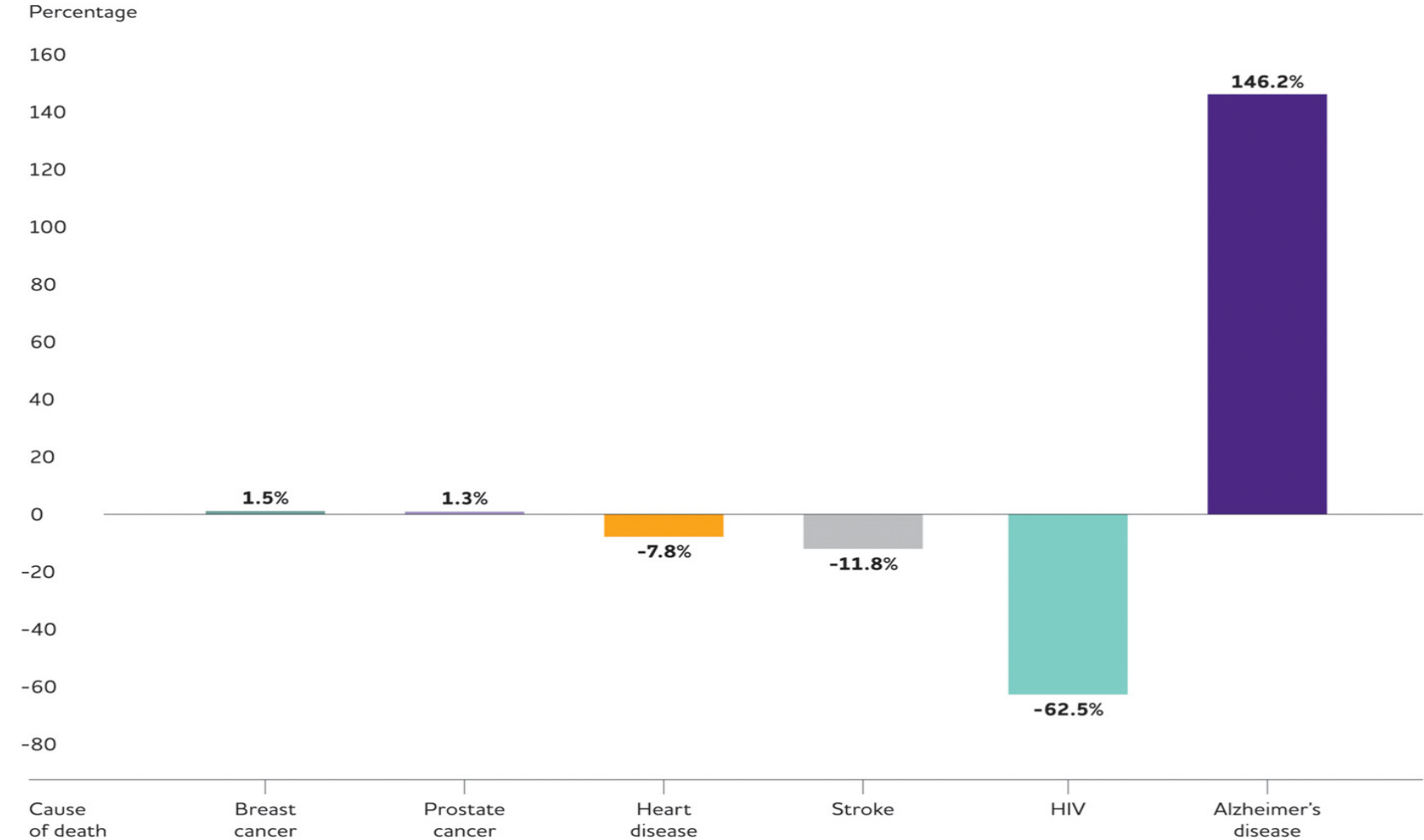
It only gets worse in a hospital or nursing home.



Happy 100<sup>th</sup>!



Percentage changes in selected causes of death (all ages) between 2000 and 2018. Created from data from the National Center for Health Statistics



# Things people say as dementia progresses

- She will not take her meds, is falling more and seems depressed.
- Her agitation is bothering others.
- He lashes out during cares.
- He can't sit still, won't sleep at night and looks mad all the time.
- She is constantly exit-seeking.

Healthy  
Brain

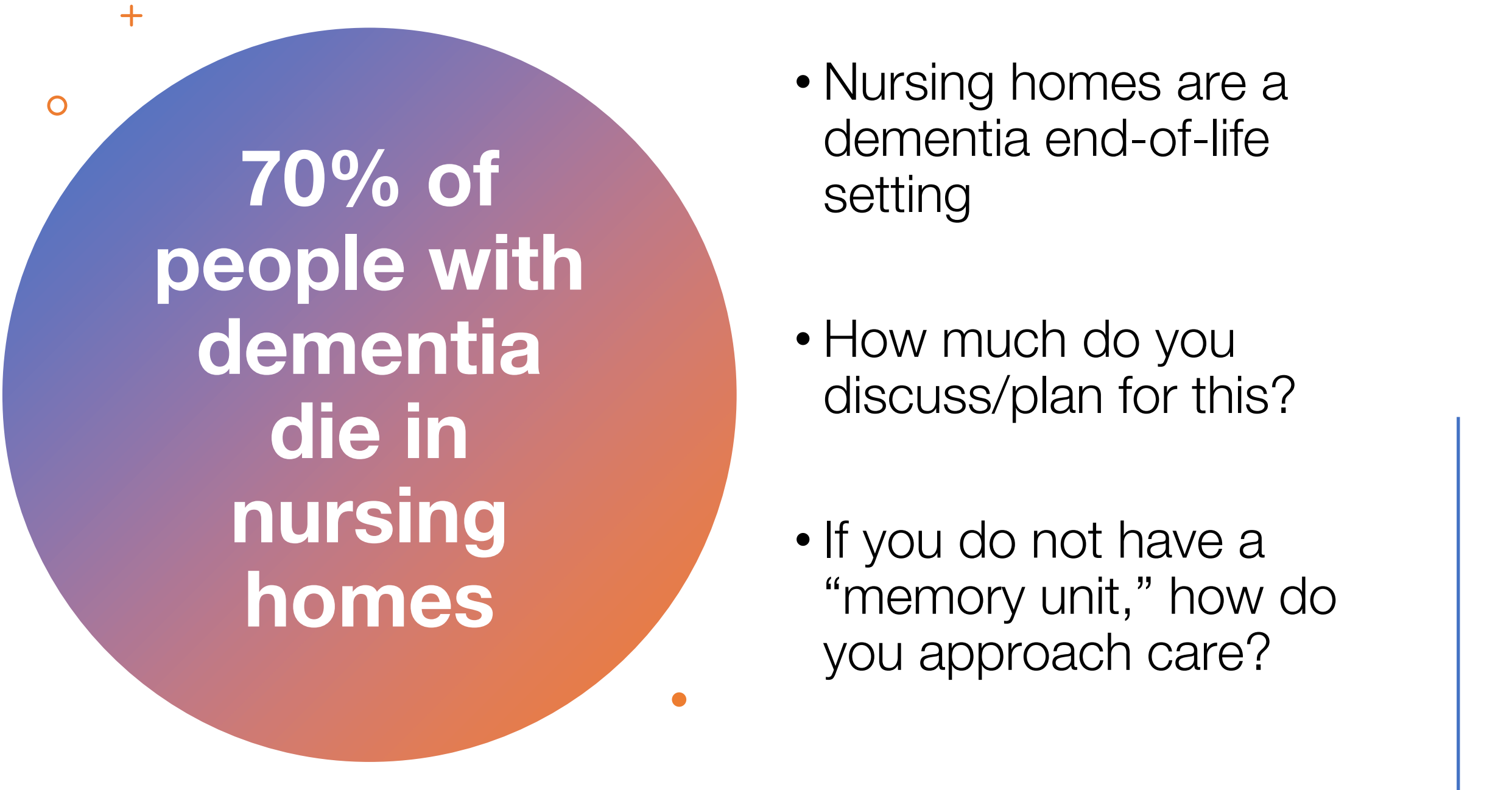
Severe  
Alzheimer's





## ***Normal (expected) events as brain dies***

- Swallowing becomes impaired
- Appetite goes down
- Unable to balance, walk
- Immunity declines
- Pneumonia
- Falls
- Weight loss



**70% of  
people with  
dementia  
die in  
nursing  
homes**

- Nursing homes are a dementia end-of-life setting
- How much do you discuss/plan for this?
- If you do not have a “memory unit,” how do you approach care?

# What is high quality end-of- life care?

Avoid hospital and  
emergency department visits

Fewer pressure ulcers

Pain addressed

Die in preferred setting



# Why are pain symptoms underreported and undertreated in dementia?

Residents lose ability to communicate

Caregivers and clinicians become habituated to “behaviors” as being part of dementia or an infection

Requires systematic assessment of non-verbal cues

**EOL outcomes  
are *better*  
when facilities  
have:**

- Dedicated dementia units
- Higher licensed staff ratios
- Non-profit designation
- Higher market competition

Orth J, Li Y, Simning A, Zimmerman S, Temkin-Greener H. End-of-Life Care among Nursing Home Residents with Dementia Varies by Nursing Home and Market Characteristics. J Am Med Dir Assoc. 2021 Feb;22(2):320-328.e4.



# Things to avoid:

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- Finger sticks and lab draws that are no longer serving goals
- Continuing medications that are no longer needed
- Showing alarm about weight loss when it is expected
- Sending to the hospital for “behaviors”
- Using antipsychotics when pain meds might be better
- Using sleeping pills when the resident prefers to sleep intermittently, not necessarily at night

**Forecast the  
path and  
promise to *care*  
until the end**

Educate

Educate family (and staff)  
about progression of  
dementia

Give

Give examples of what to expect

Establish

Establish goals of care and  
discuss specific ways to  
achieve them

Tell

Tell them your plan to keep  
resident comfortable



TOP

TEN

**1. Each human has a unique story.**

**2. Dignified care is what happens when no one is watching.**

**3. Tone of voice and body language matter more than words.**

**4. Turning down sensory input solves many problems.**

**5. Take nothing personally.**

**6. Social isolation can be deadly.**

**7. Purpose drives happiness.**

**8. Less is more on medications and medical care.**

**9. End of life is a sacred time, and a good death is possible.**

**10. Best care is grounded in compassionate presence. Without it, nothing else works.**