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Is dementia one thing or many?

How does it change over time?

4

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

5

People with mild – moderate dementia can lead fulfilling lives.

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

6

“Dementia Inside My Head”

by Gail Gregory
(living with dementia)



7

Dignity



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Unique



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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?

10

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

11



12

Alzheimer's Communication

1. Never Argue. Instead Agree.	6. Never say "I Told You." Instead Repeat.
2. Never Reason. Instead Divert.	7. Never say "You Can't." Instead say what they Can Do.
3. Never Shame. Instead Distract.	8. Never Demand. Instead Ask.
4. Never Lecture. Instead Reassure.	9. Never Condescend. Instead Encourage.
5. Never say " Remember. " Instead Reminisce.	10. Never Force. Instead Reinforce.

13



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

14



Purpose

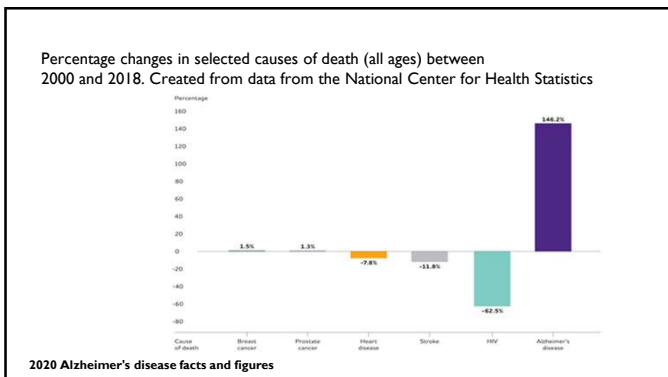
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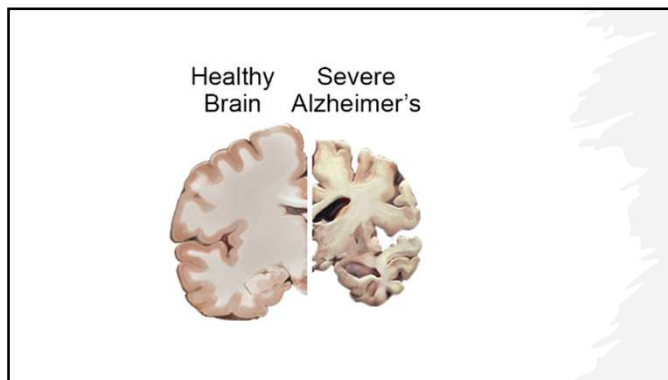


18

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.

19

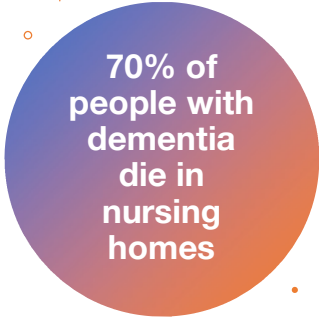


20

Normal (expected) events as brain dies

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

21



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?

22

What is high quality end-of-life care?

- Avoid hospital and emergency department visits
- Fewer pressure ulcers
- Pain addressed
- Die in preferred setting

23

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

24

EOL outcomes are *better* when facilities have:

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

Orth J, Li Y, Simring 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.

25

Things to avoid:



- 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

26

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

27



28

1. Each human has a unique story.	6. Social isolation can be deadly.
2. Dignified care is what happens when no one is watching.	7. Purpose drives happiness.
3. Tone of voice and body language matter more than words.	8. Less is more on medications and medical care.
4. Turning down sensory input solves many problems.	9. End of life is a sacred time, and a good death is possible.
5. Take nothing personally.	10. Best care is grounded in compassionate presence. Without it, nothing else works.

29
