



Spiritual Care of the Person with Dementia

Janice Hicks
Spirituality, Religion and Health
Interest Group-Penn Medicine
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www.spiritualityanddementia.org

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Dorothy Linthicum, Center for the Ministry of Teaching, Virginia Theological Seminary



outline

Healthy brain

What happens physically in dementia

Spiritual care-why and how

3 stages of Alzheimer's

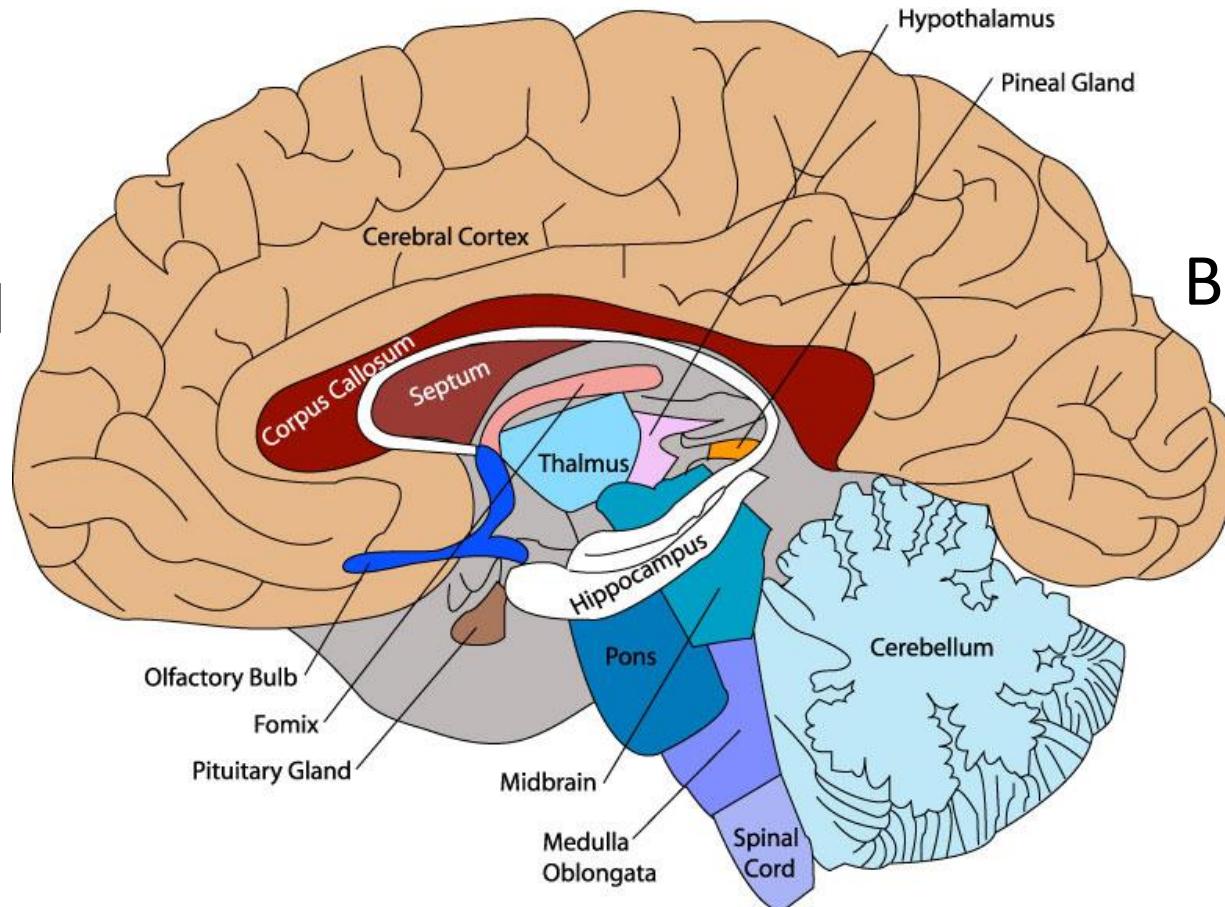
Caregivers

The healthy brain

3 pound mass of cells, neurons
Consistency of firm tofu

Forehead

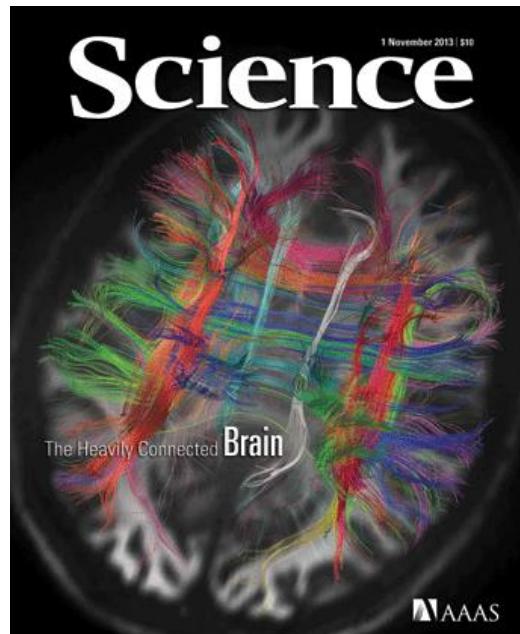
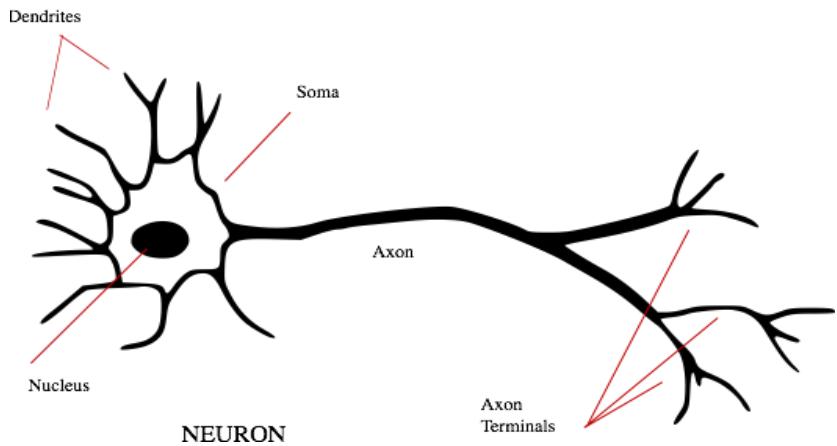
Back of head



Spinal cord

The human brain is truly astounding

- Has a billion neurons – with fibers long enough to go around the earth 4 times! Capacity of the entire internet!
Forgetfulness is NOT about filling up the hard drive
- Illness doesn't affect the whole brain and we don't know what a person is experiencing-give them benefit of the doubt



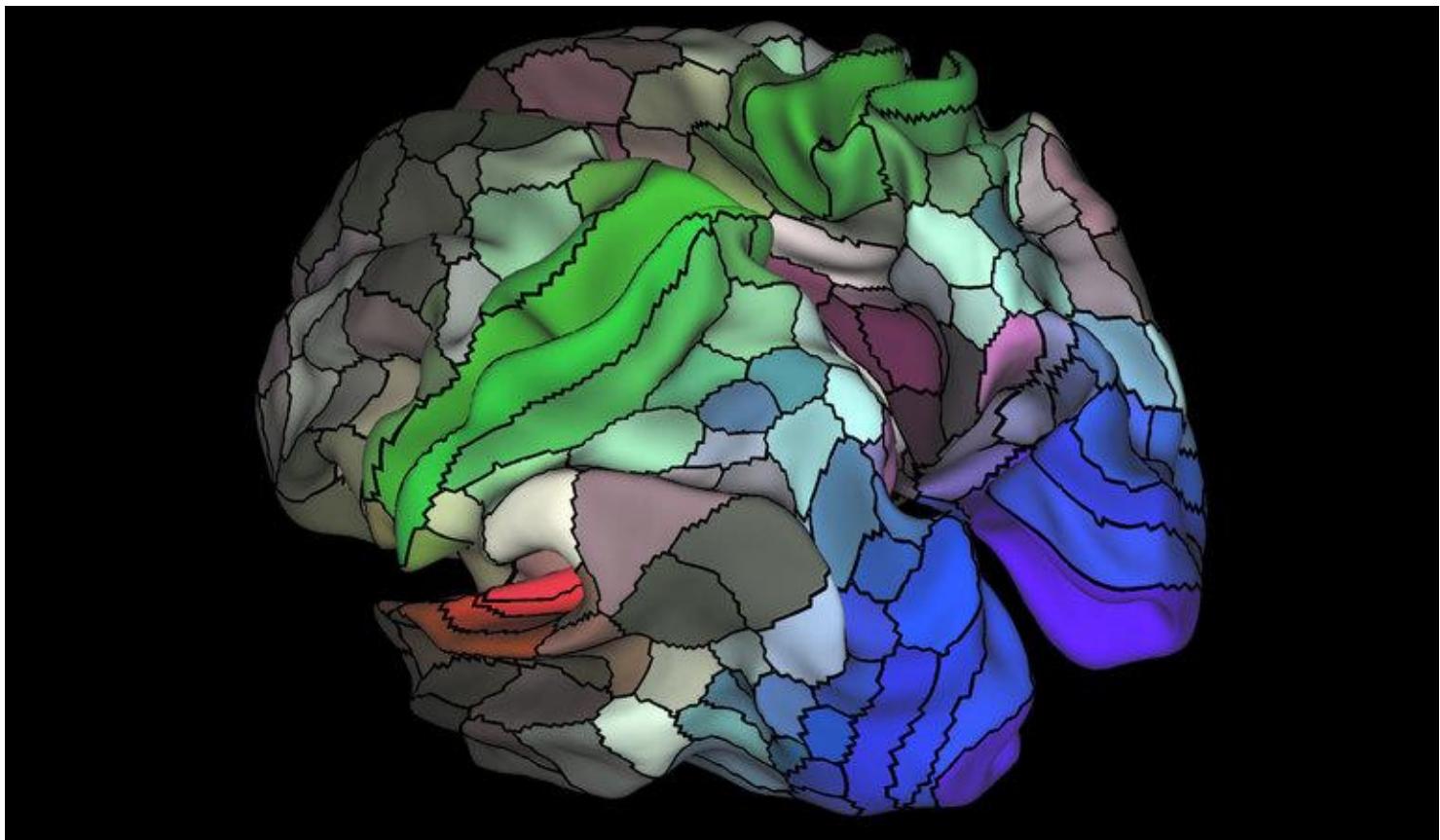
Why Sleep?



- Consolidates memories in our brain
- Cleans out worn out molecular bits that build up with the use of the brain during the day

Dementia associated with disturbed sleep

Brain Map



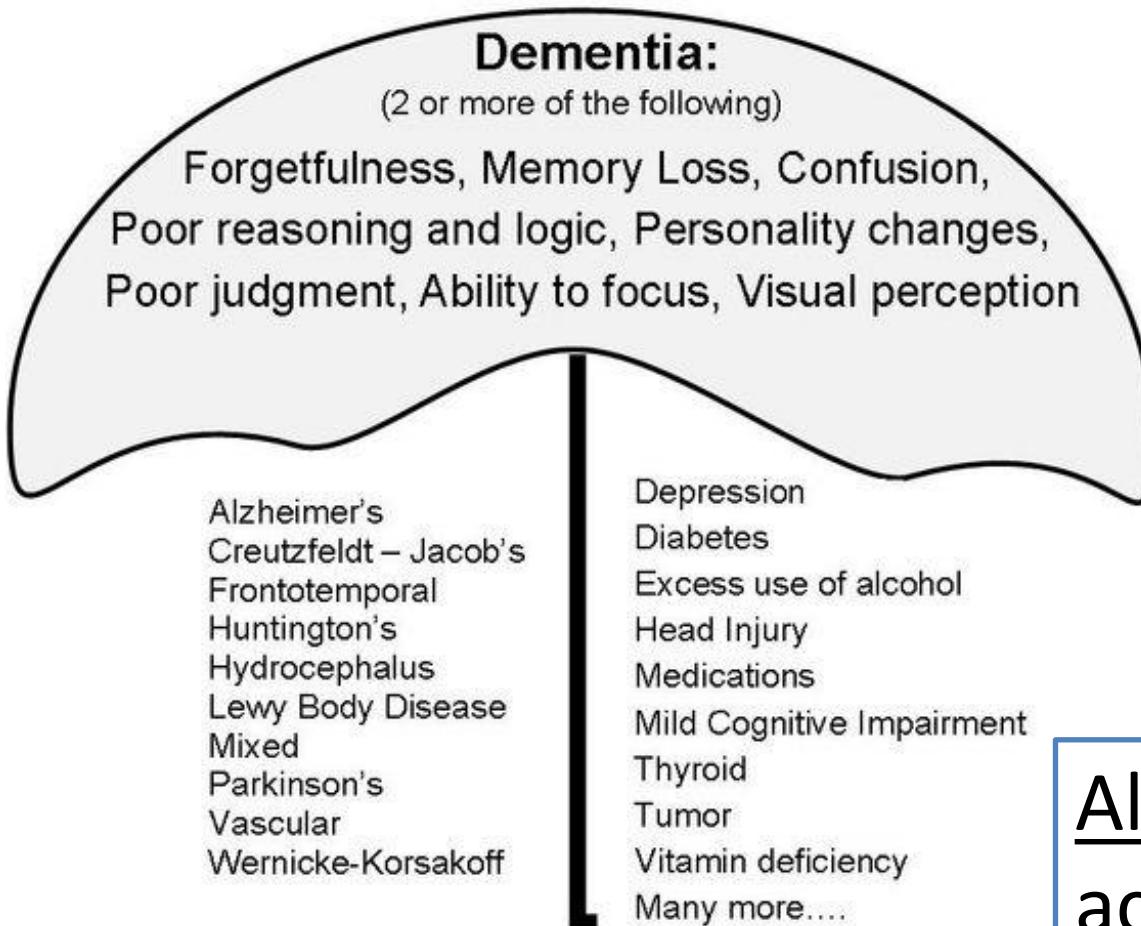
New York Times, July 20, 2016

Where is the “self”?

Where is spirituality?

No evidence that dementia can destroy the self or spirituality (or humor!)

Many illnesses cause dementia –



Alzheimer's Disease
accounts for about
60-80% of dementia.

Alzheimer's Disease

- Forgetting recently learned information, important dates
- Asking for the same information over and over
- Difficulty following a plan, working with numbers, completing daily tasks, driving
- Losing track of seasons and dates. Forgetting where you are and how you got there
- Putting things in unusual places (keys in the freezer) and losing the ability to retrace steps
- Poor decision making
- Change in mood

Normal Aging

- Forgetting names or appointments, but remembering them later.
- Sometimes having trouble finding the right word
- Misplacing things, retracing steps and finding them later

The memory-related hippocampus loses 5% of its cells every decade due to normal aging (peaks at age 25 😞)

Mild Cognitive Impairment

- Forgetting appointments or social events
- Losing train of thought, thread of conversation
- Feeling overwhelmed by making decisions, interpreting instructions
- Having trouble finding your way around familiar environments
- Becoming more impulsive or showing poor judgment
- Your family and friends notice
- But it's not severe enough to interfere with day-to-day activities

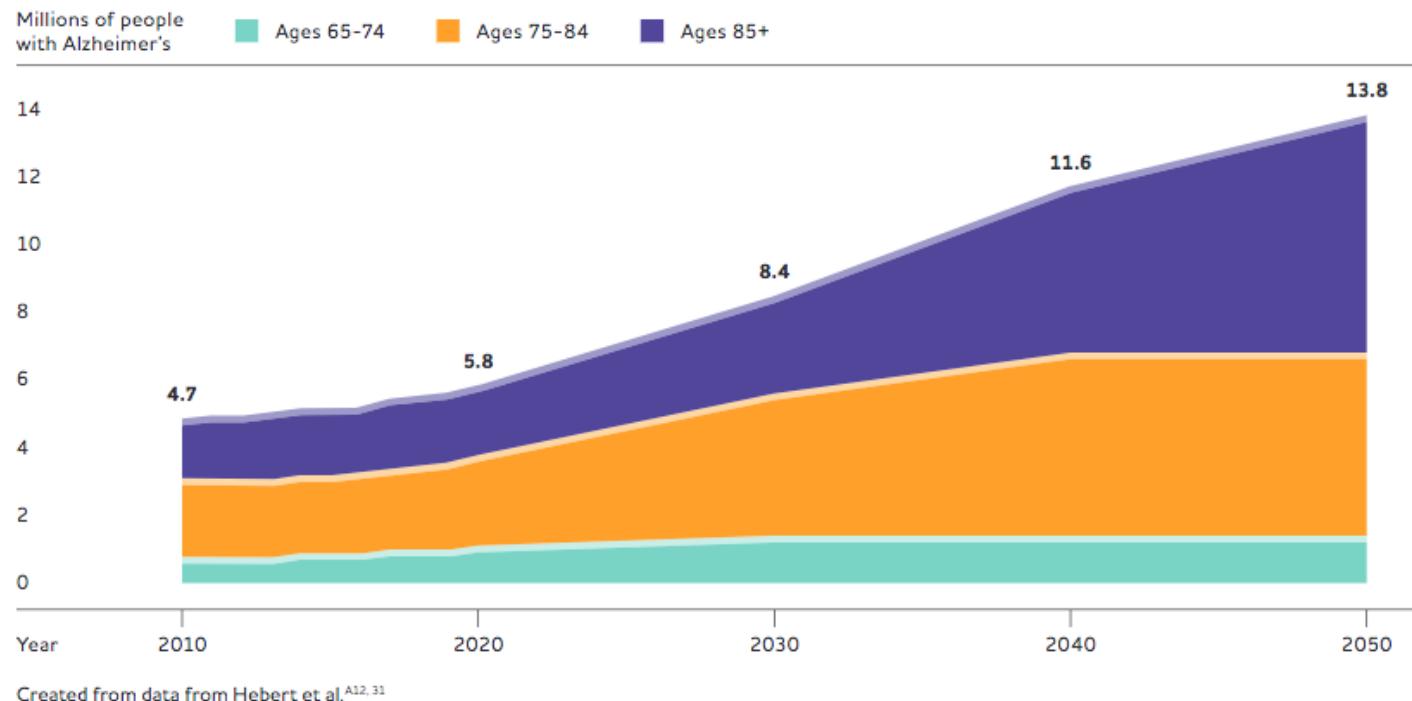
Estimated that 10-20% of adults over 65 may have MCI.

About 30% of those with MCI developed Alzheimer's in 5 years. In some individuals, it reverses or remains stable.

Alzheimer's is related to aging

3 percent of people ages 65 to 74 have Alzheimer's
17 percent of those 75 to 84
and 32 per cent of people 85 or older.
Of people who have Alzheimer's disease,
82 percent are age 75 or older.

Projected number of people age 65 and older with Alzheimer's Disease 2010 to 2050 (U.S.)



It is NOT normal aging! It is an illness – see a specialist!

Risk of Developing Alzheimer's based on demographics

Lifetime risk for women is about 20% and for men is about 10%.
(longer life? hormonal? educational differences?)

For those that make it to age 65 (Kaiser Permanente Study)

African Americans 38%

Native Americans 35%

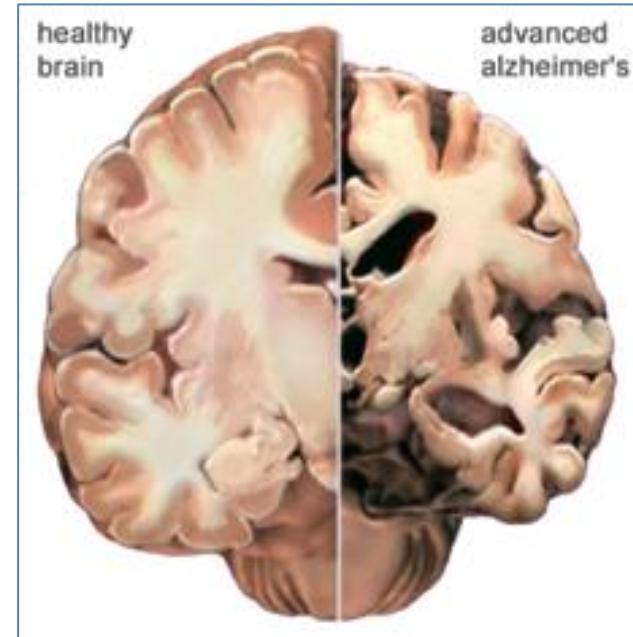
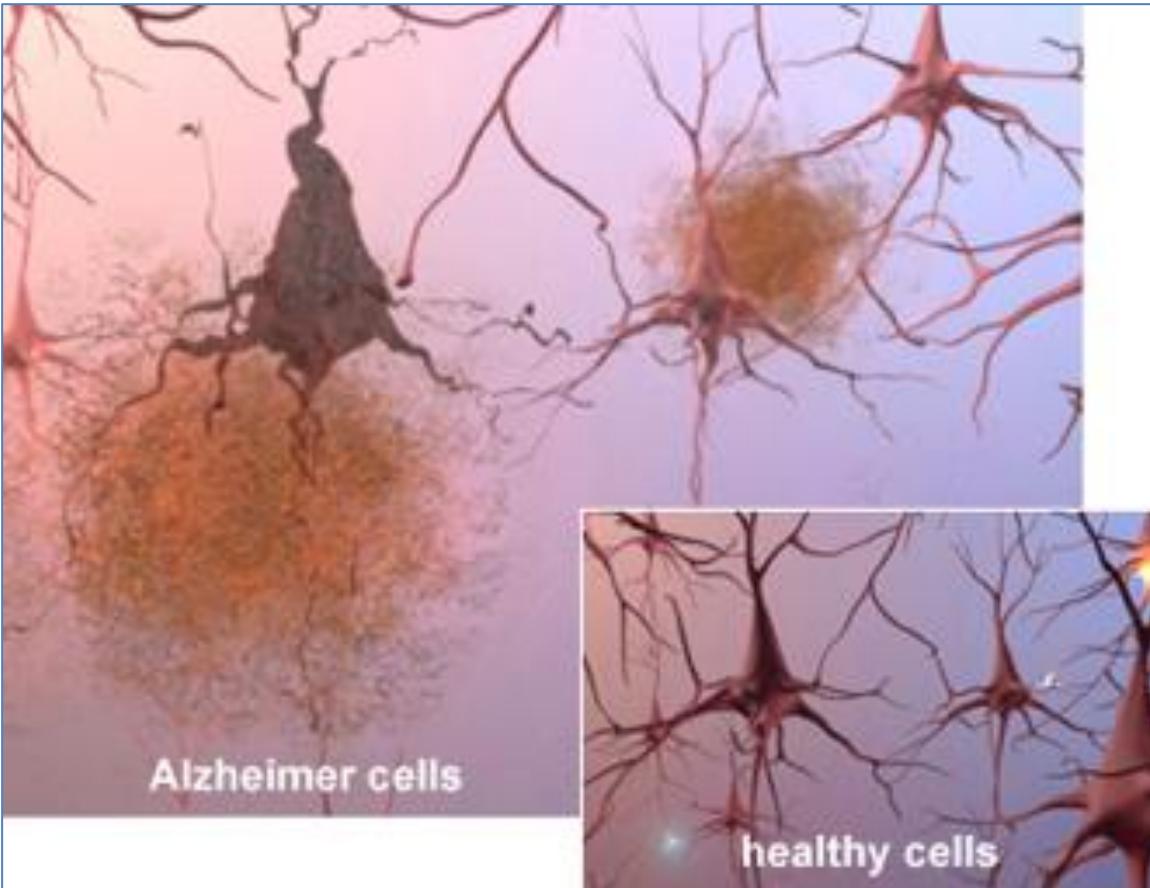
Latinos 32%

Whites 30%

Asian Americans 28%

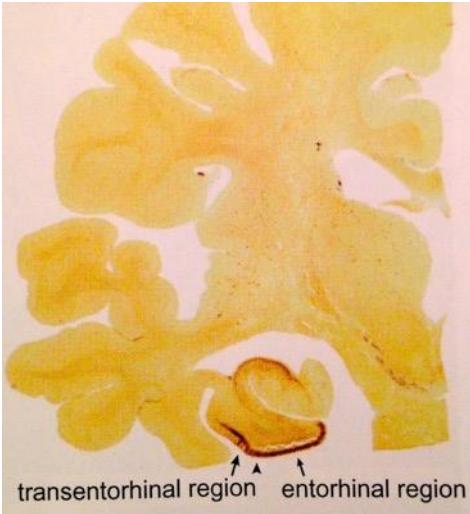
Data tracks: cardiovascular disease and diabetes, socioeconomic factors like education, poverty, early life adversity and discrimination, health care disparity.

Alzheimer's Disease – occurrence of plaques and tangles in and around neurons (no one knows the cause)

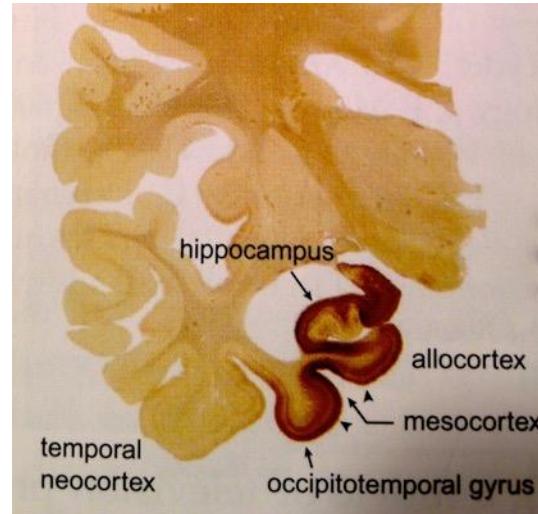


Plaque – beta-amyloid protein outside cells
Tangles – tau protein inside cells

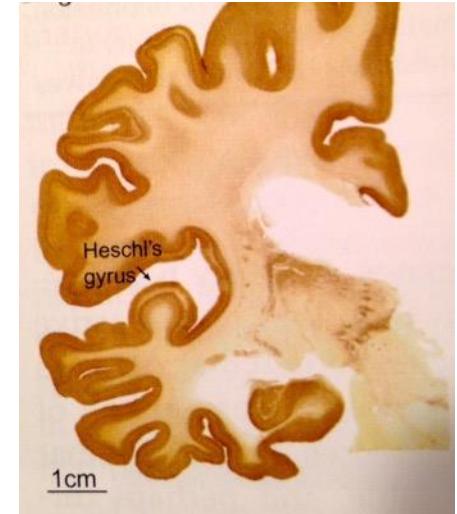
Understanding the Stages of Alzheimer's



Early stage



Middle stage



Late stage

Sweatt, David, *Mechanisms of Memory*, Amsterdam: Elsevier, 2010

Loss of short-term memory
Difficulty executing tasks:
e.g. checkbook, phone
Repetition and confusion
Wanting to “go home”
Wandering, sundowning
Person and caregiver likely in distress about the illness – anger, fear, etc.

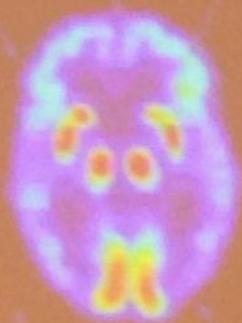
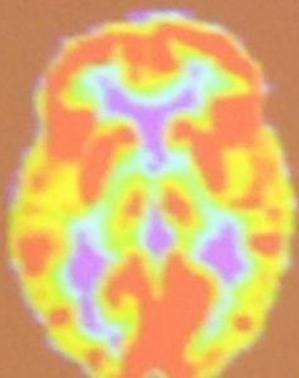
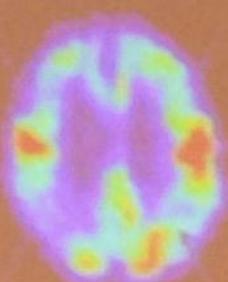
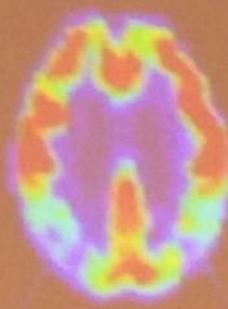
Use of long-term memory - may think they are in their childhood
Difficulty with speech
Difficulty with travel, walking, continence
More impulsive
As person forgets, it can become easier on them...harder on caregivers

Pronounced decline in cognition
Lots of sleeping/eyes closed
Inability to communicate
Needs assistance with all tasks
Prone to infections, pneumonia
When brain stem affected, life not possible
The death can be painless & peaceful
Caregivers in grief

80% of Alzheimer's patients are at home.

Positron Emission Tomography (PET) Alzheimer's Disease Progression vs. Normal Brains

| | Early Alzheimer's | Late Alzheimer's | Child |
|--------|----------------------|---------------------|-------|
| Normal | | | |



Why the stigma?

- Dementia results from a brain disease.
We don't stigmatize, say, diseases of other organs.
- We live in a culture that prizes rationality, productivity and independence, and we lose status if we don't conform. BUT:
- Our culture could learn that these are not the most important things!
- God "re-members" us
- We retain our families and community
- Abilities and capacities remain – not all is lost
- Emotional sensitivity and spiritual awareness possible
- People are LIVING WITH dementia for a long time

Why Spiritual Care?

Cognitive decline is slower for those with higher levels of spirituality and private religious practices

Kaufman et al. (2007). Cognitive decline in Alzheimer disease: impact of spirituality, religiosity, and QOL. *Neurology*, 68, 1509–1514.
N=70, MMSE = 24, Israel

Coin, A. et al. (2010). Does religiosity protect against cognitive and behavioral decline in Alzheimer's dementia? *Current Alzheimer Research*, 7, 445–452. N=64, MMSE=21, Italy

Personal spirituality correlates with quality of life in Alzheimer's

Katsuno, T. (2003). Personal spirituality of persons with early-stage dementia. *Dementia: The International Journal of Social Research and Practice*, 2, 315–335. N=23, MMSE<23, Japan.

Levels of spirituality do not decrease in early stages of dementia

Jolley, D., Benbow, S. M., Grizzell, M., Willmott, S., Bawn, S. and Kingston, P. (2010). Spirituality and faith in dementia. *Dementia: The International Journal of Social Research and Practice*, 9, 311–325. N=25, MMSE=24, England.

Beuscher, L. and Grando, V. T. (2009). Using spirituality to cope with early-stage Alzheimer's disease. *Western Journal of Nursing Research*, 31, 583–598. N=15, MMSE=18-26, United States (Arkansas)

There is a need for:

- Spiritual care in routine assessments of patients
- Education about spirituality for healthcare professionals
- Dementia training for religious practitioners.
- More research on spiritual care effects on dementia progression

Early stage – Spiritual Care

- Person still recognizes and enjoys family, friends and church; traditions, dinners out, great time for family reunion
- Lessening of inhibitions, some “blossom”
- Person can still do quite a lot (avoid doing for)
- Find out what brings them hope, purpose, what makes them feel close to God?
- What religious practices and symbols are important to the person (prayer, nature, meditation, music, icons, candles, church – make dementia friendly)
- Assure them that they will not be alone



Kathy Fogg Berry, chaplain, Westminster Canterbury, Richmond VA
her book: When Words Fail
Early Stage Dementia

See clip from CD When Words Fail

Middle Stage – Spiritual Care

- Sometimes recognizes loved ones
- Enjoys reminiscing with old photos, memorabilia
- Appeal to senses (bring objects like seashells)
- Enjoys food (maybe finger food), socializing
- Enjoys singing, reciting scripture
- Find ways to minister without words
- Assure them of God's presence and the Church's love for them
- They may not remember you visited but will feel the good feeling for a long time



Kathy Fogg Berry
When Words Fail
Middle Stage Dementia

See clip from CD When Words Fail

Late Stage – Spiritual Care

- Love, touch, music, spirituality – we don't know...
- Value the person!
- Roll with how she sounds, reflect her mood and tone
- Be fully present; synch your breath with her breath
- Spend time thanking God for this person
- Occasional coherent sentences "I'm still the same" "Don't go away"
- For people of faith, have ready familiar hymns, prayers, scriptures and sacraments
- "And the things of Earth will grow strangely dim..."



<https://www.youtube.com/watch?v=CrZXz10FcVM>

Kathy Fogg Berry
When Words Fail
Late Stage Dementia

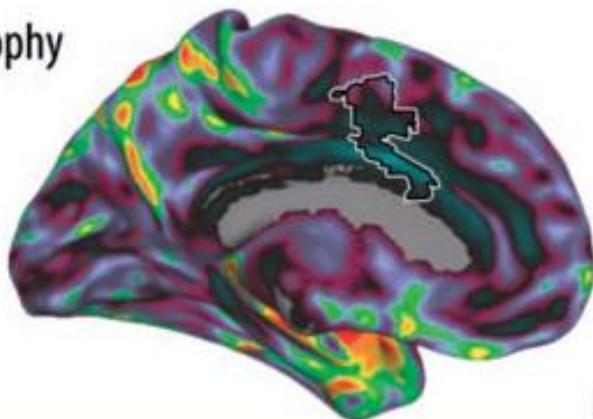
See clip from CD When Words Fail

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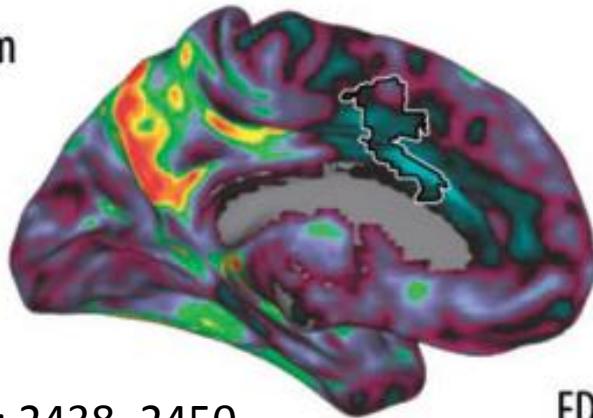
Musical Memory
Region-of-Interest



Grey Matter atrophy



Hypometabolism



Music – emotion!

Right hemisphere – melody
and harmony

Left – rhythm and language

Playing instrument or dancing
– also involves motor system

The section of the brain
responsible for long-term
musical memory is
relatively unaffected by
Alzheimer's, often well
into the late stages.

Use songs from the
person's youth
(hymns, top 10 Hits,
oldies, nursery rhymes)

Damage
Purple – lowest
Green – low
Yellow-higher
Orange -highest

FD

Caregivers need spiritual support too:
Loretta Woodward Veney
her book: Being My Mom's Mom



<https://www.youtube.com/watch?v=bSqHfVYPIbo>

For Caregivers

“I see that [people living with dementia] still have the potential to inspire us, teach us, love us, heal us, amuse us, befriend us, calm us, touch us, energize us, enlighten us, empower us, forgive us, nurture us, open our hearts, bring out the best in us, and bring meaning and purpose into our lives. We may be surprised to realize that persons with Alzheimer's still have the capacity to show us how to be humble and trusting and courageous and receptive; how to be authentically ourselves in this present moment; how to be guileless, innocent and completely without sin.”

“My Mom's diagnosis and her predictable decline called for me to overcome my fearful reactions about Alzheimer's...But I chose to go very close to this illness and to stay with my mom forever. The result of those choices became an unexpected and precious love story that will be mine for the rest of my life.”

Memory Café

- An informal event that provides a relaxing environment for people with dementia and their care partners, a respite from the illness; provides “normalcy.” Not a support group per se.
- Invented by Dr. Bere Miesen in the Netherlands in 1997 – social engagement for quality of life
- Hugely successful in England, just starting in U.S.
- Helps to end the isolation of people with dementia and fight the stigma
- Often light food and drink, activities, entertainment, especially music
- Usually once a month
- People with dementia find support and respite
- Caregivers build bonds with others for peer support and friendship and may experience renewal
- Volunteers can become advocates; “Everyone LOVES LOVES LOVES having student volunteers!”
- Might extend the time a person can remain at home
- Disparity in access to support for people with dementia

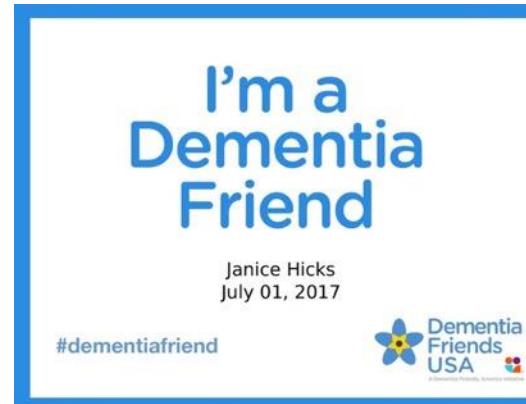


Resources

Teepa Snow
dementia training:

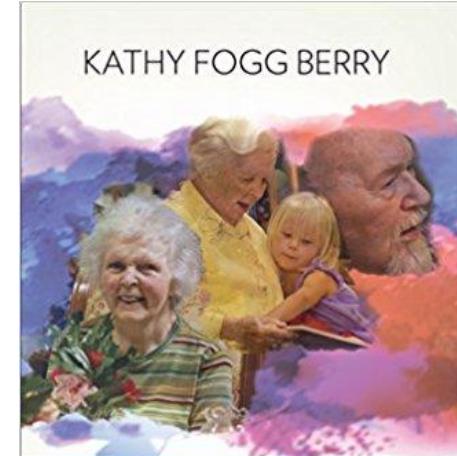


Become a
Dementia Friend:



I am curating materials at:
Spiritualityanddementia.org
Would love your feedback
and questions!

Book
and
DVD



When Words Fail

*Practical Ministry to People
with Dementia and Their Caregivers*

A screenshot of the 'SPIRITUALITY AND DEMENTIA' website. The header includes links for Home, About, Science and Theology, Dementia Friendly Congregations, Our Picks, and Contact. The main content area has a section titled 'Science, theology and stories can help us understand the physical, emotional, and spiritual aspects of dementia. What do we understand about the stages of the disease and what is happening in the brain? Does dementia impact a person's identity as a person of faith or an atheist or in between? How can we use these insights for better care and better advocacy for people with dementia? Learn more by exploring this site and the resources under "our picks."'. Below this are three columns: 'Science of Dementia' (with an image of a brain), 'Theology of Dementia' (with an image of Jesus Christ), and 'For Congregations' (with an image of a church). A sidebar on the right contains text about the September 17, 2016 Conference at St. Margaret's Episcopal Church, Dupont Circle, Washington DC, and a 'Read more' button.

Risk Factors for Developing Alzheimer's Disease: Non-modifiable

Most A's is caused
by multiple factors.

Genetic (inherited)

- <1% of people with A's have genes associated with early Alzheimer's (before age 65)
- People with Down syndrome over age 65, >75% get Alzheimer's

- Older age (but it is not normal aging! It is a disease.)
- Family history
- APOE-e4 gene
(40-65% of people with A's have 1-2 copies of this)
- Traumatic brain injury (falls, car accidents)
chronic blows to head (sports) suspected

Modifiable Risks for Alzheimer's

(caution, not following these guidelines does not cause Alzheimer's! but Alzheimer's cases worldwide could be reduced by one third if these were controlled)



- Healthy diet – good fats, lean proteins, lots of vegetables, low sugar, low carbs, hydration, (gut microbiome)
- Regular physical activity- very beneficial! 50% effect!
- Good sleep habits
- Management of cardiovascular risk factors (diabetes, obesity, smoking and hypertension)
- Management of depression and stress
- Lifelong learning/cognitive training
- Social and cognitive engagement – learn new things!

Beta-amyloid appears a decade before diagnosis

