Spiritual Care of the Person with Dementia

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www.spiritualityanddementia.org

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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

Where is the “self”?  Where is spirituality?

No evidence that dementia can destroy the self or spirituality (or humor!)
Many illnesses cause dementia –

Dementia:
(2 or more of the following)
Forgetfulness, Memory Loss, Confusion, Poor reasoning and logic, Personality changes, Poor judgment, Ability to focus, Visual perception

Alzheimer’s
Creutzfeldt – Jacob’s
Frontotemporal
Huntington’s
Hydrocephalus
Lewy Body Disease
Mixed
Parkinson’s
Vascular
Wernicke-Korsakoff

Depression
Diabetes
Excess use of alcohol
Head Injury
Medications
Mild Cognitive Impairment
Thyroid
Tumor
Vitamin deficiency
Many more….

Alzheimer’s Disease accounts for about 60-80% of dementia.
<table>
<thead>
<tr>
<th>Alzheimer’s Disease</th>
<th>Normal Aging</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Forgetting recently learned information, important dates</td>
<td>• Forgetting names or appointments, but remembering them later.</td>
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<tr>
<td>• Asking for the same information over and over</td>
<td>• Sometimes having trouble finding the right word</td>
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<tr>
<td>• Difficulty following a plan, working with numbers, completing daily tasks, driving</td>
<td>• Misplacing things, retracing steps and finding them later</td>
</tr>
<tr>
<td>• Losing track of seasons and dates. Forgetting where you are and how you got there</td>
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<tr>
<td>• Putting things in unusual places (keys in the freezer) and losing the ability to retrace steps</td>
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<td>• Poor decision making</td>
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<td>• Change in mood</td>
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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

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

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.

It is NOT normal aging! It is an illness – see a specialist!
Risk of Developing Alzheimer’s based on demographics

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Risk Percentage</th>
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<tbody>
<tr>
<td>African Americans</td>
<td>38%</td>
</tr>
<tr>
<td>Native Americans</td>
<td>35%</td>
</tr>
<tr>
<td>Latinos</td>
<td>32%</td>
</tr>
<tr>
<td>Whites</td>
<td>30%</td>
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<tr>
<td>Asian Americans</td>
<td>28%</td>
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</table>

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

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

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

http://www.alz.org/braintour/plaques_tangles.asp
Understanding the Stages of Alzheimer’s

Early stage
- 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.

Middle stage
- 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

Late stage
- 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

<table>
<thead>
<tr>
<th>Normal</th>
<th>Early Alzheimer’s</th>
<th>Late Alzheimer’s</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Normal Brain" /></td>
<td><img src="image2.png" alt="Early Alzheimer’s Brain" /></td>
<td><img src="image3.png" alt="Late Alzheimer’s Brain" /></td>
<td><img src="image4.png" alt="Child Brain" /></td>
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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

N=70, MMSE = 24, Israel

N=64, MMSE=21, Italy

Personal spirituality correlates with quality of life in Alzheimer’s

N=23, MMSE<23, Japan.

Levels of spirituality do not decrease in early stages of dementia


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

https://www.youtube.com/watch?v=bSqHfVYPIbo
“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.”

From The Rev. Jade Angelica
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!
Risk Factors for Developing Alzheimer’s Disease:
Non-modifiable

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

Most A’s is caused by multiple factors.

From: 2016 Alzheimer’s Disease Facts and Figures, Alzheimer’s Association
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

(Sperling et al. 2011)