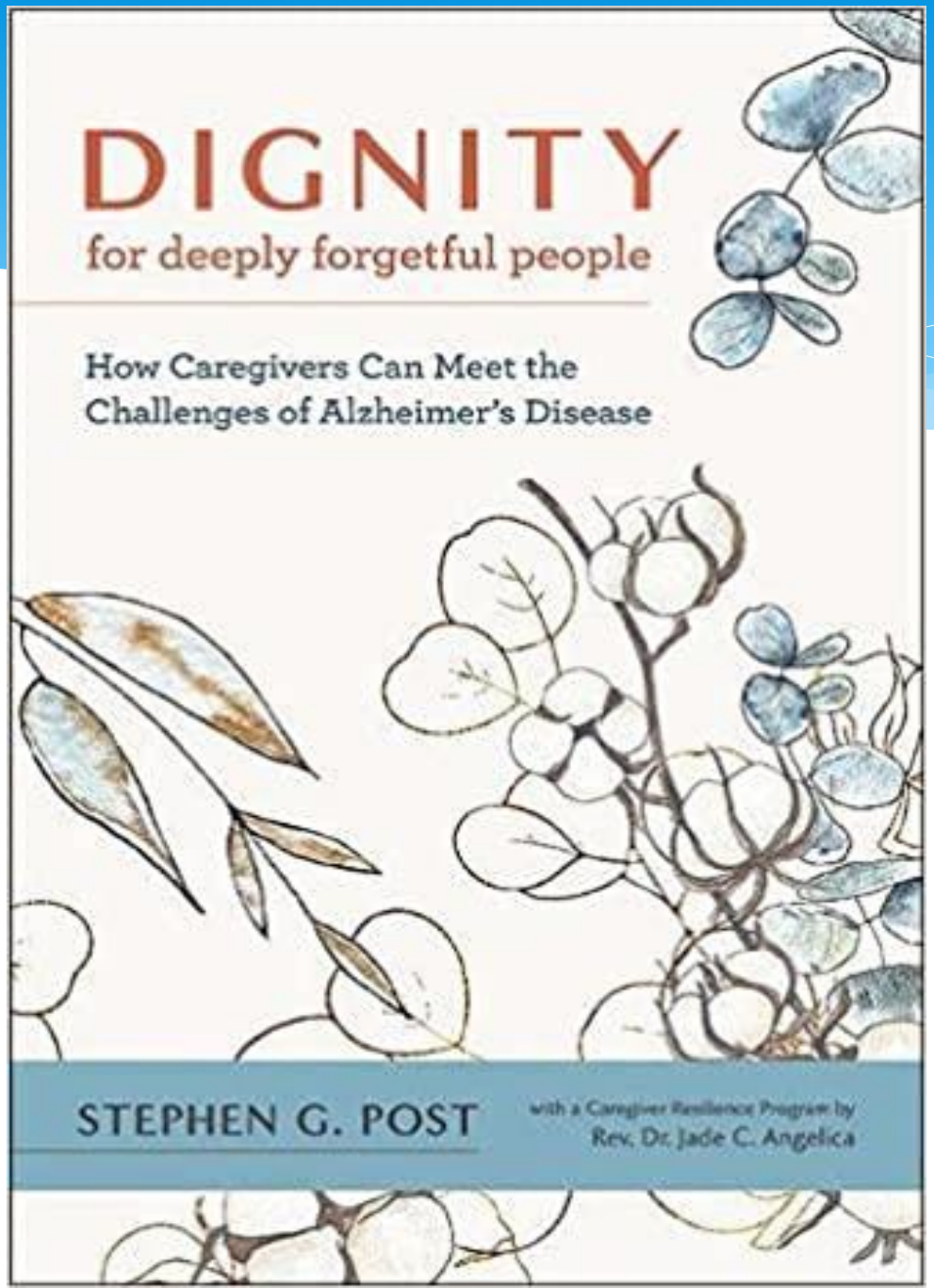
DIGNITY FOR DEEPLY FORGETFUL PEOPLE: HOW CAREGIVERS CAN MEET THE CHALLENGES OF ALZHEIMER'S DISEASE

Stephen G. Post 2021


DIGNITY
for deeply forgetful people
How Caregivers Can Meet the Challenges of Alzheimer's Disease
STEPHEN G. POST
with a Caregiver Resilience Program by
Rev. Dr. Jade C. Angelica

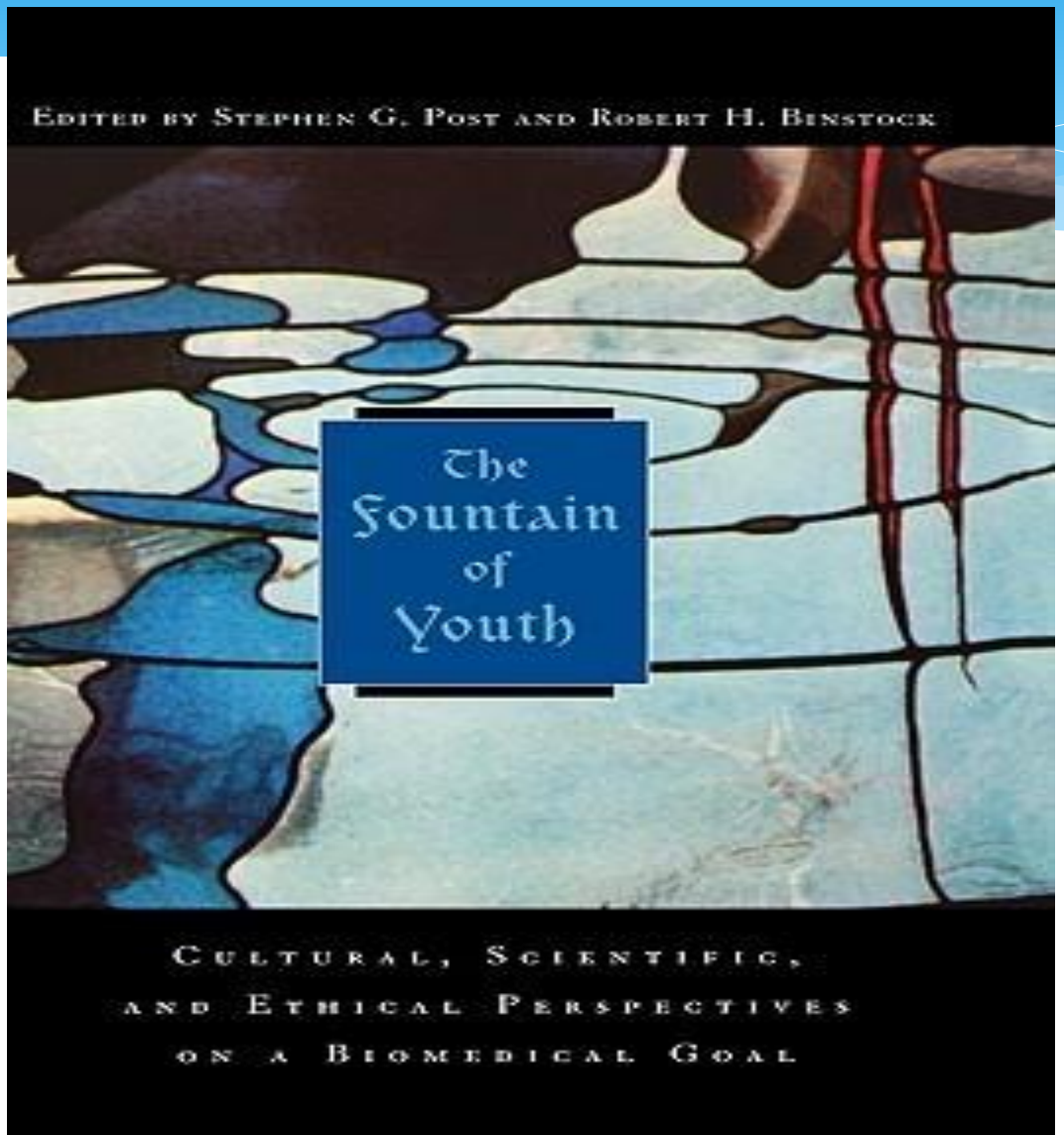
"Dementia" is a "Syndrome," Caused by Many "Diseases"

* A century ago in the U.S. dementia was mainly secondary to syphilis (neuro-syphilis) as life *expectancy* was much lower
* Now in our aging society age itself is the strongest predictor of AD, Parkinson's, Vascular or "multi-infarct" dementia, etc.
* Frontotemporal dementia, chronic traumatic encephalopathy (CTE), and "early onset AD (presenilin 1 & 2 genes)" are not old age-related. The youngest case of probable AD is age 25.
* Down syndrome (those who live to 50 will likely have a "dual diagnosis" of DS-AD, a "double whammy" for parents
* Dr. Alzheimer himself did not think he had discovered a new disease, but rather an inevitable aspect brain aging should we live long enough

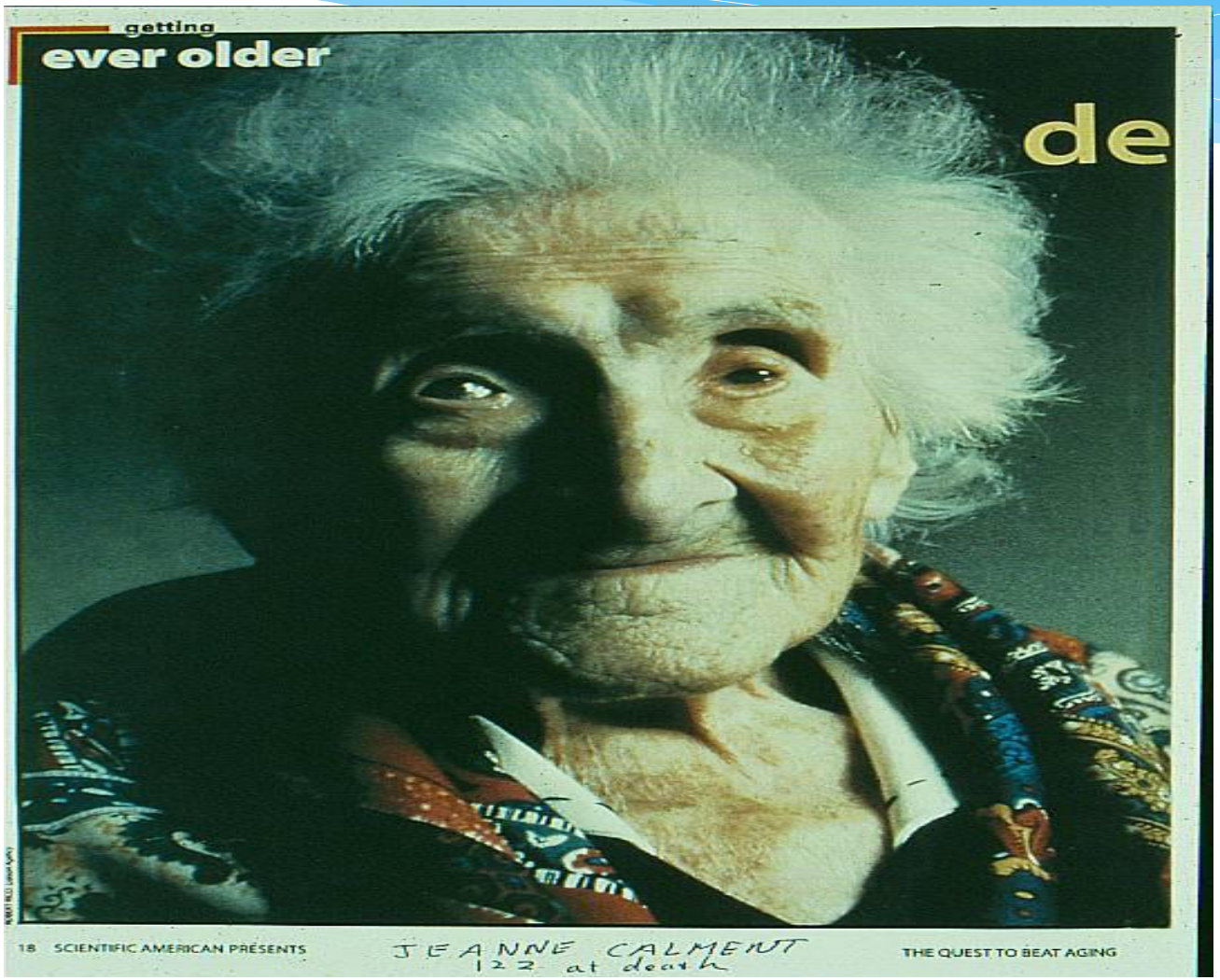
Epidemiology: The Aging Society is no Picnic

* Today est. 5 million Americans living with probable AD, but often a "mixed diagnosis" especially with vascular dementia
* 3% at age 65, doubles every five years, est. 18% at age 80 (60% + women age 95 to 100)
* African-American and Hispanic populations slightly higher incidence than Caucasians
* Japan life expectancy 88+, so highest numbers
* Two thirds women who live longer than men on average
* Intergenerational Justice?

The New Atlantis (Frances Bacon, 1626) with "Waters of Paradise"

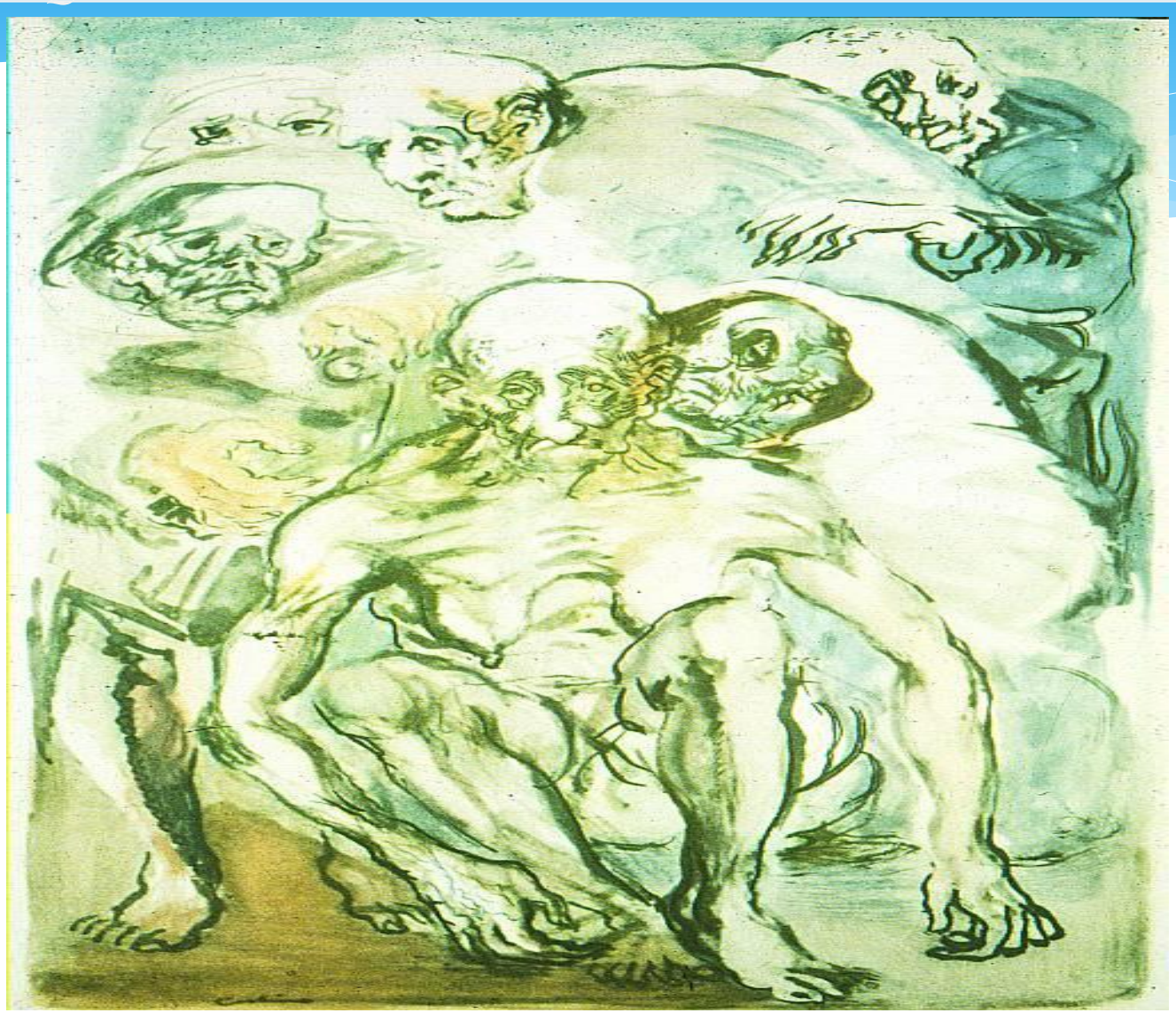


Is "senile dementia" a normal part of aging (if we all lived long enough)?



DIGNITY:

"THE QUALITY OF BEING WORTHY OF HONOR AND RESPECT"



Jonathan Swift's Dystopian Immortality (*Gulliver's Travels 1726 vs. The New Atlantis 1626*)

* "They are despised and hated by all sorts of people; when one of them is born, it is reckoned ominous and their birth is recorded very particularly."
* "They were the most mortifying sight I ever beheld, and the women more horrible than the men."
* "…my keen appetite for perpetuity of life much abated."
* "…send a couple of struldbrugs to my own country, to arm our people against the fear of death."

Jonathan Swift- Saint for Deeply Forgetful People: St. Patrick's Hospital

* "Not fear but care" (Bethlehem/Bedlam)
* No pelting, prodding or cooling (Sermon on the Mount)
* In "the vicinity of general medical care" (St. Steven's)
* Residents from Dublin area so family can visit
* In 1742, after writing his will, Swift himself succumbed to dementia that he feared, leaving his ten thousand pounds to build St. Patrick's, which is today a renowned venue for compassionate dementia care across Ireland

Saint Patrick's Hospital

He left the little wealth he had
To build a house for fools and mad;
Showing in one satiric touch
No nation needed it so much.

— from "Verses on the Death of Dr Swift", 1731

Jonathan Swift's concern for the mentally ill began in London, where he was governor of the Bethlehem Hospital (Bedlam). Swift was horrified by the practice of putting "mad" inmates on display to amuse the public.

While he was Dean of St Patrick's, Swift decided to found a hospital for mental patients. In the 1730s, he began to search for suitable sites. Finally he settled on a place near Dr Steeven's Hospital, which offered general medical care. Swift drew up a constitution to govern the hospital and, with typical wit, summed up his great project in the rhyme shown on this panel.

In 1742, following a stroke, Swift himself was declared "of unsound mind and memory". He died three years later, leaving £12,000 for the founding of St Patrick's Hospital. The hospital continues to be one of the leading psychiatric institutions in these islands.

"Hypercognitive Values" (SGP, 1995) Tiergartenstrasse 4, Berlin, 1939-41

* 70,273 in asylums killed in hypothermia "research" (dementia + developmental intellectual disabilities)
* "Life unworthy of life" "Useless eaters" (along with Jews, Gypsies, Gays, etc.)
* Western philosophies of rationalist personhood made worse by eugenics
* Dr. Leo Alexander ("voluntary associations")
* Disability research indicates that some physicians still assume that cognitive strength gives life its worth. Almost all western philosophers assume this.

The New England
Journal of Medicine

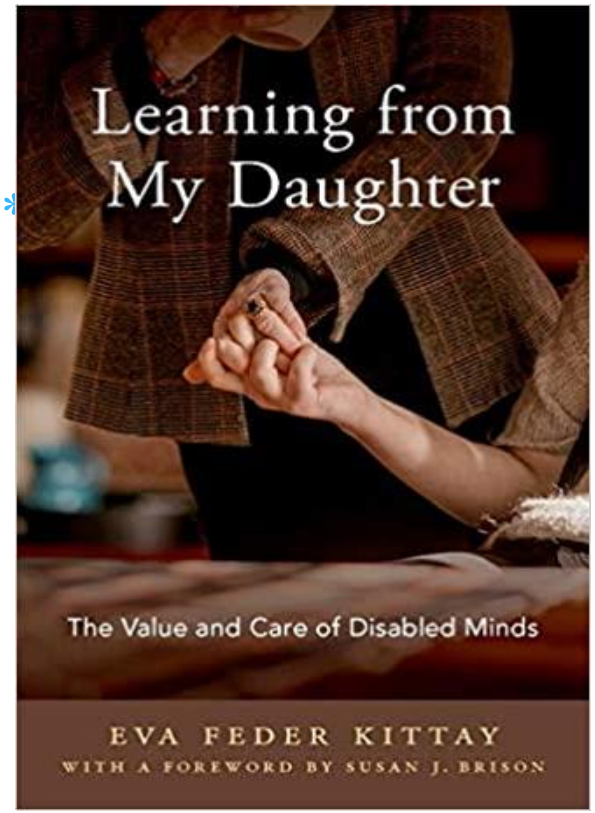
JULY 14, 1949

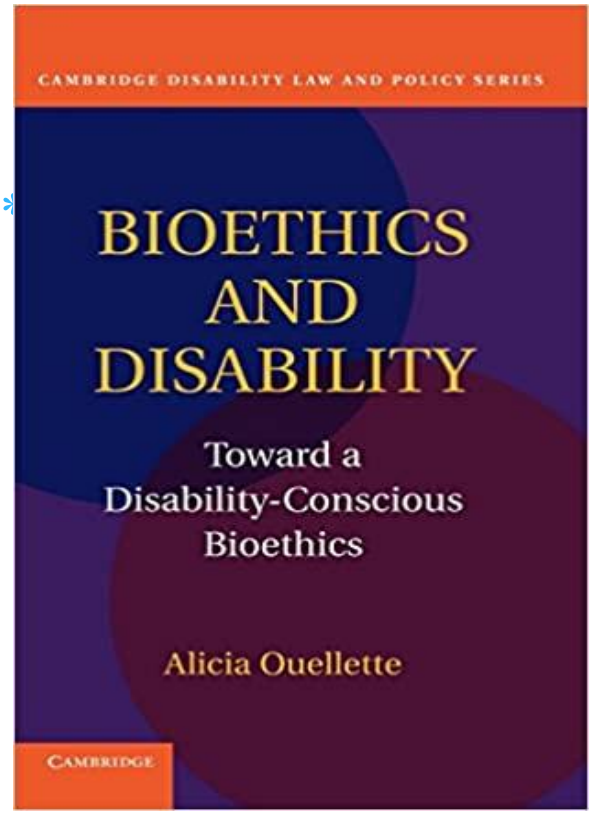
MEDICAL SCIENCE UNDER DICTATORSHIP

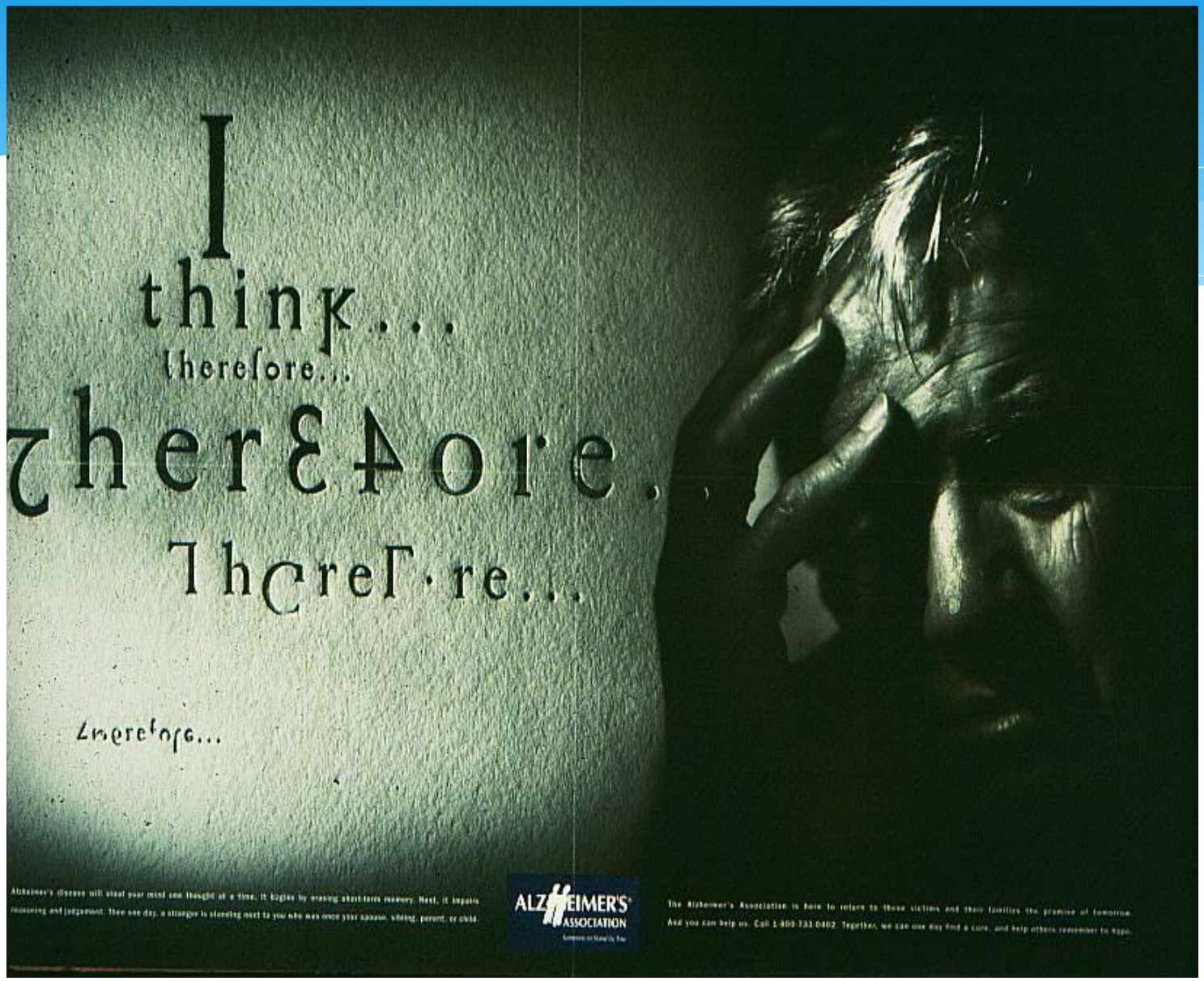
LEO ALEXANDER, M.D.*

BOSTON

Disability Advocates vs Bioethics





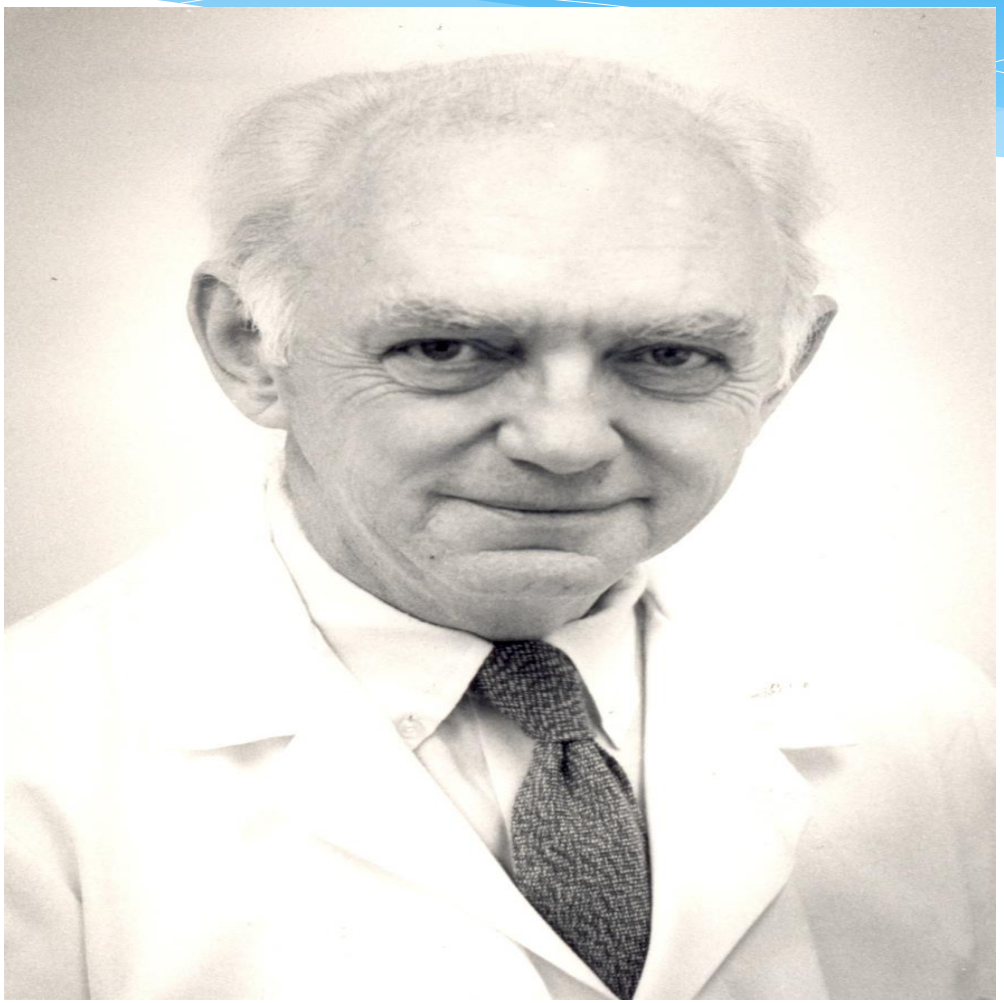

I think...
therefore...
therefore...
Therefore...
Therefore...
ALZHEIMER'S ASSOCIATION

CONSCIOUSNESS & "DEEPLY FORGETFUL PEOPLE" (SGP 1995): Indian Institute for Advanced Studies, Bangalore 2015

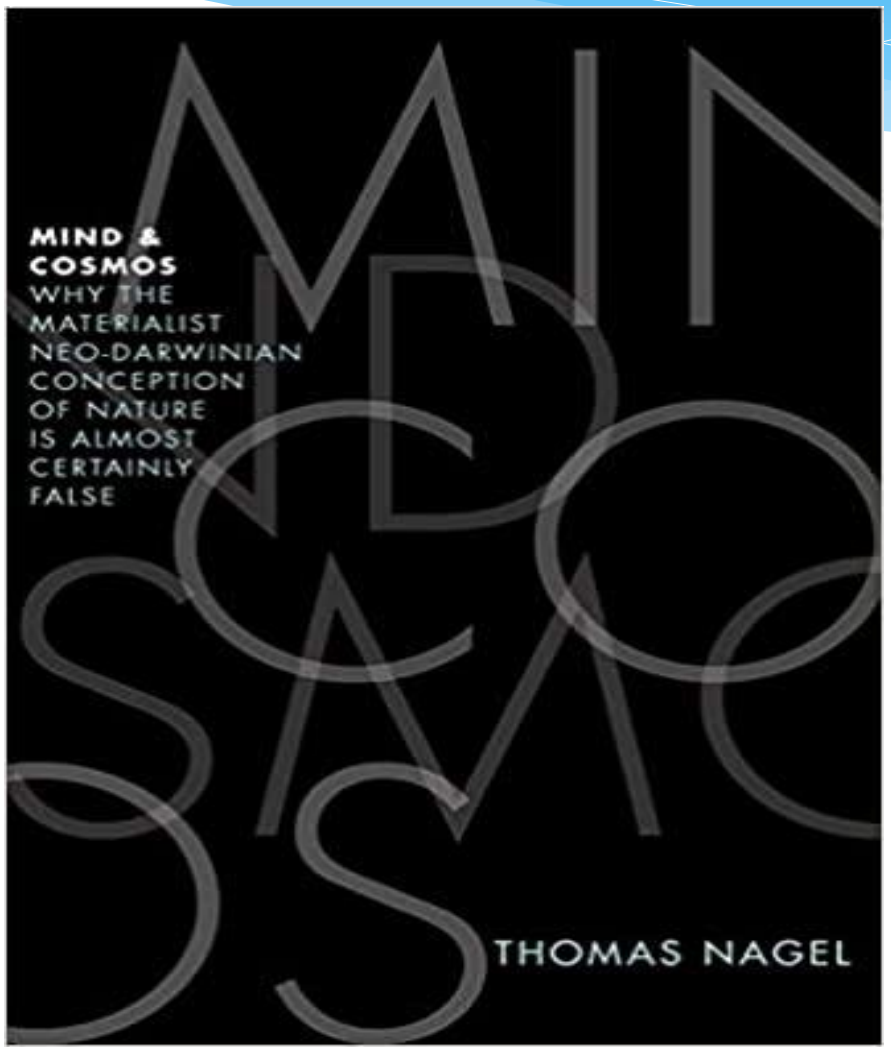
WHY "DEEPLY FORGETFUL" RATHER THAN "DEMENTIA"?

* "Dementia" is a too negative term, capturing decline from a former mental state, and often used derisively
* "Deeply Forgetful" is a term of inclusivity, of affirmation on a continuum of forgetfulness, and even of spiritual mystery beneath a veneer of chaos or silence (Augustinian: we are all forgetful of our Source)
* "Paradoxical lucidity" (SGP 1995)
* Mind and self-identity present despite neurological adversity
* "I am convinced that nothing can ever separate us from God's love." (*Romans 8:31*)

Jim's Twig at Heather Hill: He Remembered Whose He Was



What Is Mind? Nagel, *Mind* & *Cosmos*



“Paradoxical Lucidity”

* “Consciousness unexplained: end-of-life lucidity in dementia patients” Rudolph Tanzi MD Harvard Neurologist

* Rudi Tanzi, MD www.youtube.com/watch?v=ud77u9xuDro

'Paradoxical lucidity: A potential paradigm shift for the neurobiology and treatment of severe dementias'

Alzheimer's & Dementias, Vol. 15, No. 8, 2018

* "Unexpected cognitive lucidity and communication in patients with severe dementias, especially around the time of death, have been observed and reported anecdotally. Here, we review what is known about this phenomenon, related phenomena that provide insight into potential mechanisms, ethical implications, and methodologic considerations for systematic investigation."

* Hindu friends with their *Namaste* in Mt. Vernon, Ohio

* “In this issue of *Alzheimer's & Dementia*, Mashour et al. propose the intriguing hypothesis that some manifestations of late-stage dementia are reversible, albeit transiently. Calling this phenomenon paradoxical lucidity, their paper follows a 2018 workshop sponsored by the National Institute on Aging that assessed the state of knowledge on lucidity in dementia and identified areas ripe for further study. **The National Institute on Aging has since released two funding opportunity announcements (RFA-AG-20-016 and RFA-AG-20-017)** to establish the building blocks of such a research program. … Research may … uncover novel mechanisms underlying cognitive decline, identify potential preventive or therapeutic approaches…, offer more effective strategies for caregivers, and perhaps even expand our understanding of the nature of personhood and consciousness.”

Vignette 1

* Leonard Slatkin conducts *Appalachian Spring* (u-tube)
* https://www.youtube.com/watch?v=bMaAe2aH6pw


"So long as the human spirit thrives on this planet, music in some living form will accompany and sustain it and give it expressive meaning."
Aaron Copland

Vignette 2

* In that late stage when words are gone except for those very occasional moments, she looked at me intently and said forcefully, “God, physics and the cosmos.”
* Olivia Hoblitzelle (2008), author of *Ten Thousand Joys & Ten Thousand Sorrows: A Couple’s Journey Through Alzheimer’s* emailed me on 12 April 2013, a few days after we shared a panel together at the Times Center in Manhattan for the New York Alzheimer’s Association’s *Charles Evans Lecture.*

Musicandmemory.org/Poetry/Art

* Medial Prefrontal Cortex (just behind the forehead) links memory, music and emotion
  (Petr Janata, "The Neural Architecture of Music-Evoked Autobiographical Memories," *Cerebral Cortex*, Vol. 19, 2009, p. 2579-2594)
* https://www.youtube.com/watch?v=5FWn4JB2YLU

What Hypercognitive Philosophies of Personhood Fail to Notice

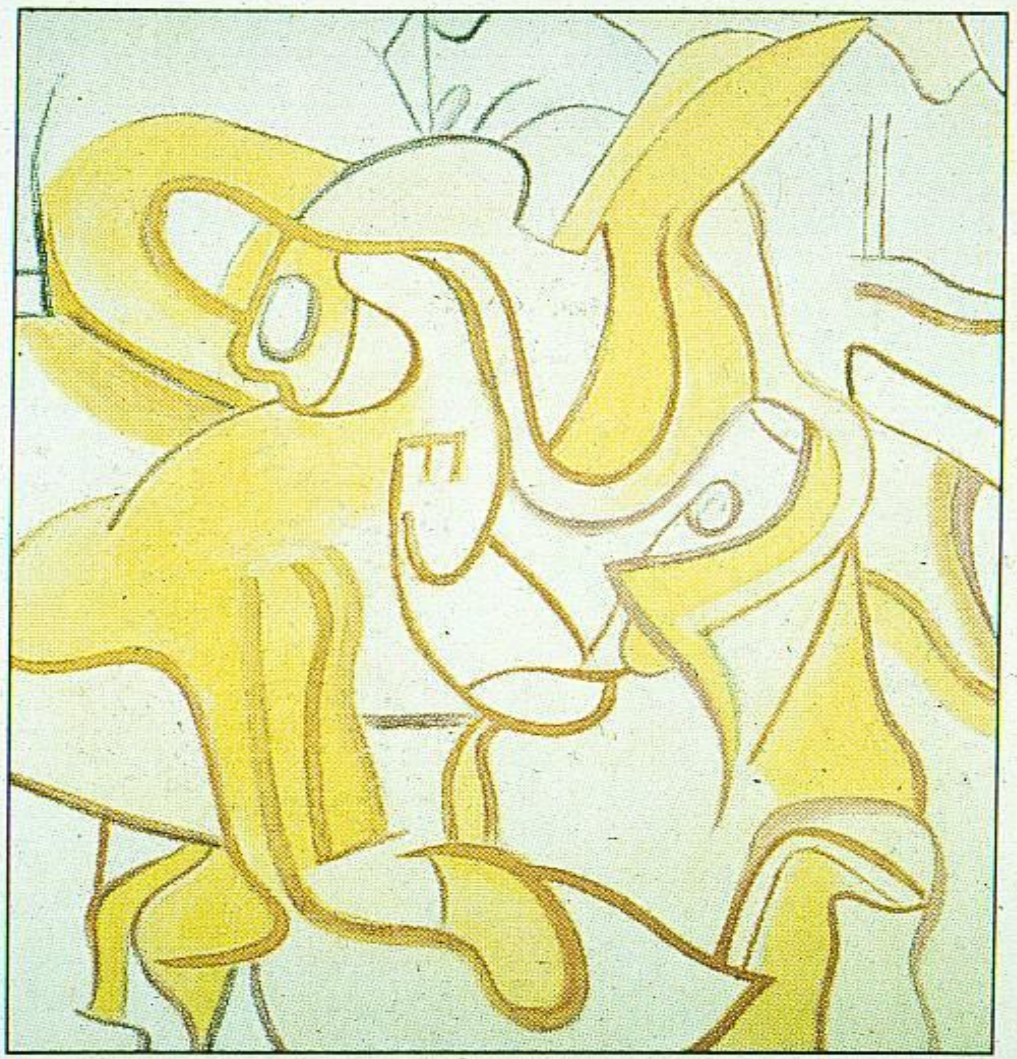
* Creativity
* Symbolic Rationality
* Emotion
* Relationality (including dogs)
* Mirth
* Somatics
* Music & Rhythm
* Beauty
* Smell/taste
* Spirituality?
* Touch (tactile)
* Consciousness
* Continuity of Self-Identity

Creativity: de Kooning

'Woman, I' *(1950–52) Beyond the first great abstractions*

'Untitled' *(1987)*

How much of the artist's hand?



Tactile & Relational: Dogs to the Rescue

Marvin and Lola

* Good afternoon Dr. Post,
* Bringing Lola to see Alzheimer's patients has made a tremendous difference in helping me open up the line of communication. Take Marvin , who is 91 and lives at home with his wife. He has advanced AD. He has a full time aide and sleeps in his own room while his wife has the master bedroom. Marvin had walked into her bedroom and fell asleep in the bed since the morning… The aide and his wife couldn't get him up. I walked in the room with Lola, put her paws up on him and said "Marvin get up, look who came to visit." Marvin popped up excited to see Lola. I was able to lure him out of bed and into the family room where his wife was. He couldn't contain his excitement. His wife and the aide couldn't believe it. Lola brought back his memory of his dog Sparky!! (Meryl Berdugo)

www.dogs4dementia.com.au

* Dogs 4 Dementia is the first time in Australia that expert Dementia Centre consultants have partnered up with skilled Assistance Dogs Australia trainers to place dogs into the homes of people living with dementia. A dog is carefully chosen to match household personalities and trained to meet their specific needs.

Symbolic Rationality

* Jim's twig, de Kooning's brush
* "Linear rationality" is **not morally important.** It is rationality as a source of self-identity that matters – i.e., "who" we are matters more than "how" we proceed
* Joe's Rosary

Assume that Grandma's Still There (not a "shell," "husk," etc.) and so be Kind & Hopeful

* Hope in AD = Being open to surprises and noticing continuity of selfhood (esp. inspiring for caregivers)

"... talk even to the most cognitively disabled, calling them by name. Speak with a warm and calm voice, with a joyful facial expression, bending down to make eye contact, communicating with them rather than around them."

SGP, "Alzheimer's & Grace" *First Things*

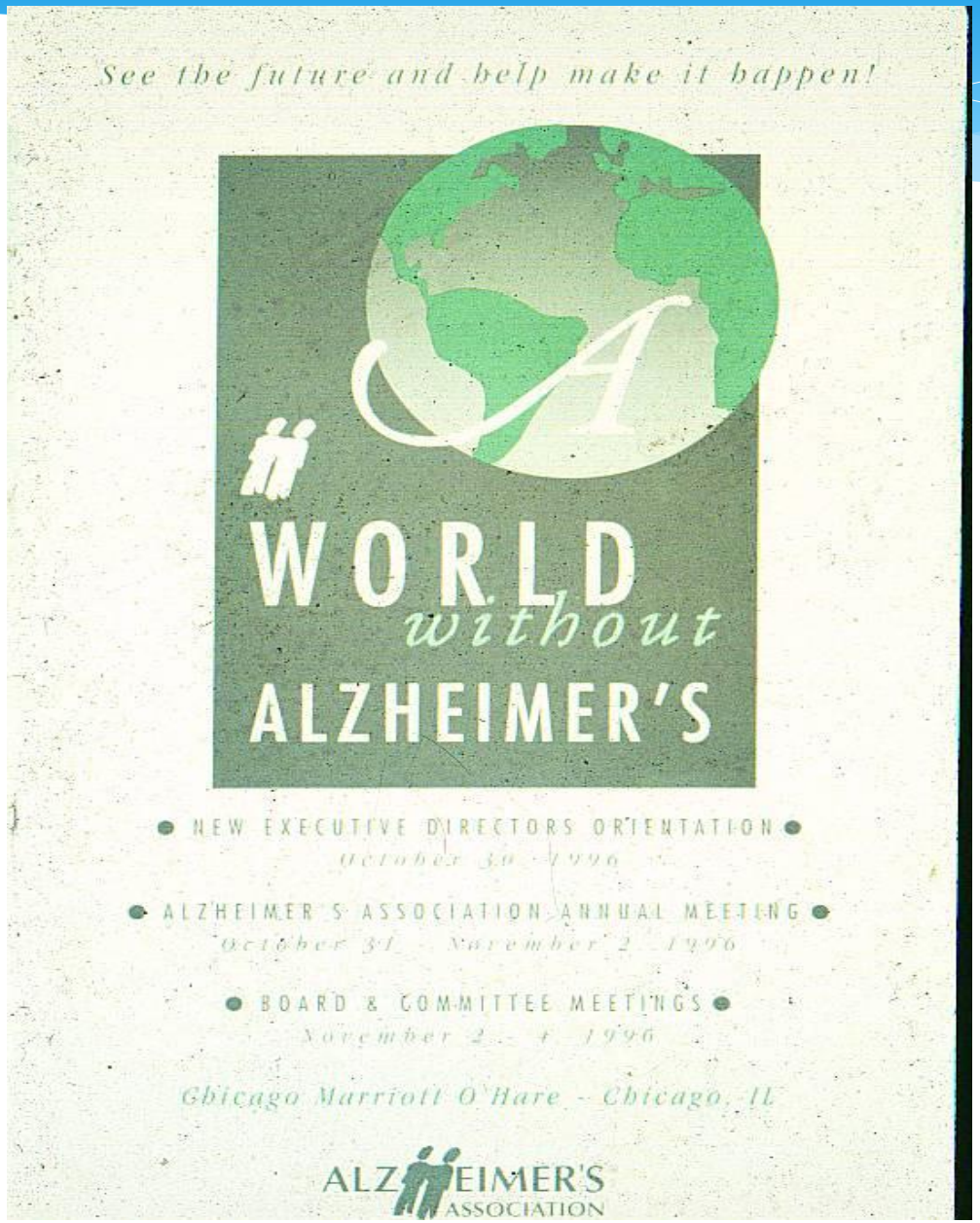
DFP Pick Up on Kindness (Jim and Rebecca's Doll)

WWW.UNLIMITEDLOVEINSTITUTE.ORG

* “One fine night in June 1933 I was sitting on a lawn after dinner with three colleagues, two women and one man. We liked each other well enough but were certainly not intimate friends, nor had anyone of us a sexual interest in another. Incidentally, we had not drunk any alcohol. We were talking casually about everyday matters when, quite suddenly and unexpectedly, something happened. I felt myself invaded by a power which, though I consented to it, was irresistible and certainly not mine. For the first time in my life I knew exactly – because, thanks to the power, I was doing it – what it means to love one’s neighbor as oneself. I was also certain, though the conversation continued to be perfectly ordinary, that my three colleagues were having the same experience. (In the case of one of them, I was able later to confirm this.) My personal feelings towards them were unchanged – they were still colleagues, not intimate friends – but I felt their existence as themselves to be of infinite value and rejoiced in it.” WH AUDEN “The Protestant Mystics”

BIOMEDICAL FRUSTRATIONS

- "Currently, no evidence of even moderate scientific quality exists to support the association of any modifiable factor (such as nutritional supplements, herbal preparations, dietary factors, prescription or nonprescription drugs, social or economic factors, medical conditions, toxins, or environmental exposures) with reduced risk of Alzheimer's disease."
- http://consensus.nih.gov/2010/alzstatement.htm

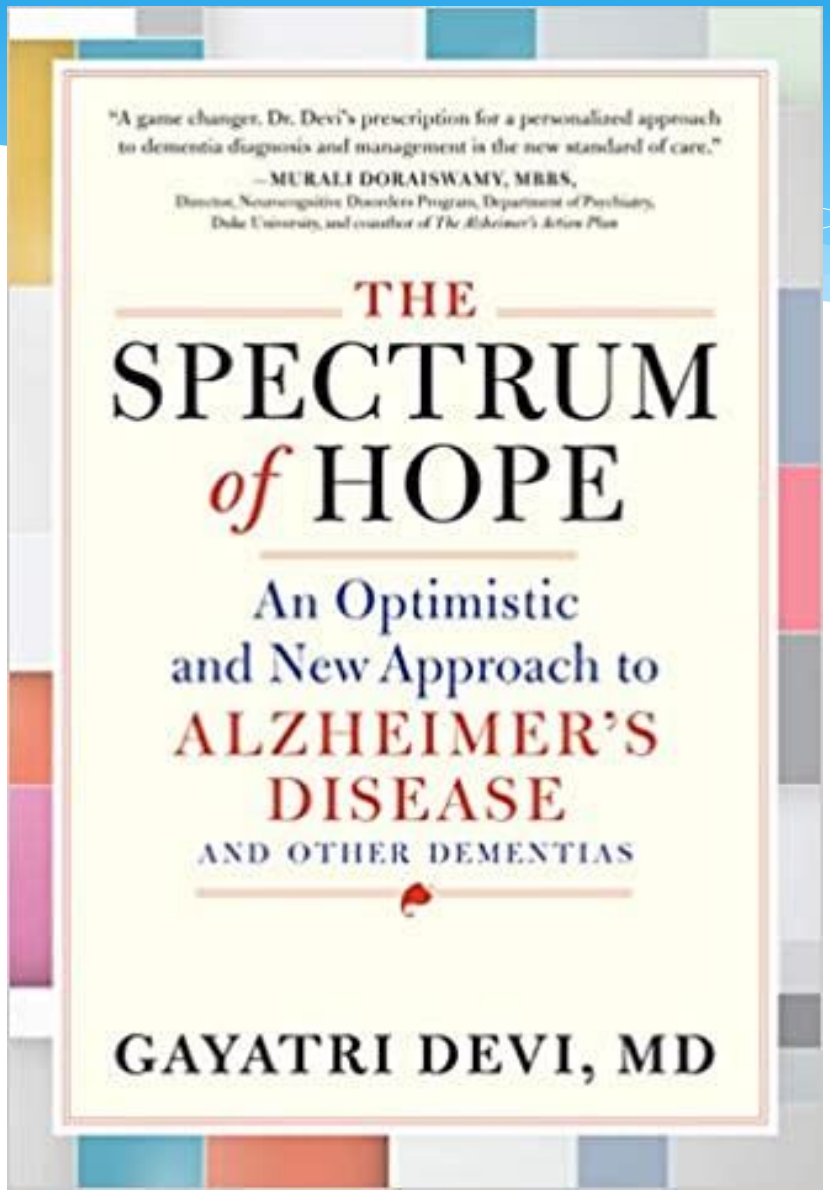

See the future and help make it happen!
WORLD
without
ALZHEIMER'S
NEW EXECUTIVE DIRECTORS ORIENTATION
October 30 - 1996
ALZHEIMER'S ASSOCIATION ANNUAL MEETING
October 31 - November 2 - 1996
BOARD & COMMITTEE MEETINGS
November 2 - 4 - 1996
Chicago Marriott O'Hare - Chicago, IL
ALZHEIMER'S
ASSOCIATION

Newly Failed Preventive Intervention

* Biogen's "aducanumab" is another monoclonal antibody that binds to hard amyloid plaques. 2021 voted down (0 yes, 10 no, 1 uncertain) by FDA expert panel in November 2020, and FDA approveda few months later. It requires IV administration.
* No impact in pre-symptomatic use of cholinesterase drugs in people with "MCI" (pre-AD)
* *Estrogen replacement* does not delay AD onset in women at high risk based on family history
* No benefit in use of *ibuprofen* or others NSAIDs, *Ginko Biloba*, …possible vitamin D perhaps.

Rx: Healthy Aging

* Mediterranean Diet/greens and fruits
* Exercise
* Social and intellectual engagement
* Walk peacefully with friends to a Greek restaurant and then play poker, etc.
* Meditation to destress (Dharma S Khalsa MD) www.alzheimersprevention.org
* Consider a dementia dog
* MusicandMemory.org
* Worship – Janet Keck at Yale Div


"A game changer. Dr. Devi's prescription for a personalized approach to dementia diagnosis and management is the new standard of care."
—MURALI DORAISWAMY, MBBS,
Director, Neurocognitive Disorders Program, Department of Psychiatry, Duke University, and coauthor of The Alzheimer's Action Plan
THE
SPECTRUM
of HOPE
An Optimistic and New Approach to
ALZHEIMER'S DISEASE
AND OTHER DEMENTIAS
GAYATRI DEVI, MD

Prevention? Age with Purpose

* Older adults who rated high quartile on a purpose of life scale had 30% lower rate of cognitive decline than the low quartile (PA Boyle et al., "Effect of Purpose in Life on the Relation Between Alzheimer Disease Patholigic Changes on Cognitive Function in Advanced Age," *Archives of General Psychiatry*, Vol. 69 (no. 5), 2012, pp. 499-504)

ETHICAL QUANDARIES

- Enrollment in Research (tacrine blood draws)
- Diagnostic Disclosure (Murray)
- Autonomy and Safety
- Restrictions on Driving (Leo)
- Autosomal Genetic Testing – PS1, PS2 (Gale in Chicago)
- Susceptibility Testing (REVEAL APOE-e4, esp. e4/e4)
- Advance Planning (durable power of attorney for healthcare)
- Intimacy in Nursing Homes
- Pain!
- Nutrition & Hydration

Look for Pain: Bias Hurts

* Prevalence of pain in elderly nursing home residents (est. half of whom have dementia) is 40-80% (e.g., arthritis and other chronic conditions)

Scales for Assessing Pain (2000!)

* Scales focus on **breathing** (labored, noisy, hyperventilating), **vocalization** (moaning, crying out), **facial expression** (frightened, frowning, grimacing), **body language** (curled up, clenched fists, tenseness, pushing away caregivers, rubbing), **behaviors** (agitation, irritability, sleeping patterns, loss of appetite, crying, wandering)
* Pain Assessment in Advanced Dementia (**PAINAD**) scale can be used in several minutes

Adult Children: A Different Stage of Life

Older Persons' Opinions About Life-Sustaining Procedures in the Face of Dementia

Dwenda K. Gjerdingen, MD; Jennifer A. Neff, MD; Marie Wang; Kathryn Chaloner, PhD

Objective: To investigate the attitudes of cognitively normal older adults toward various life-sustaining procedures in the face of dementia.

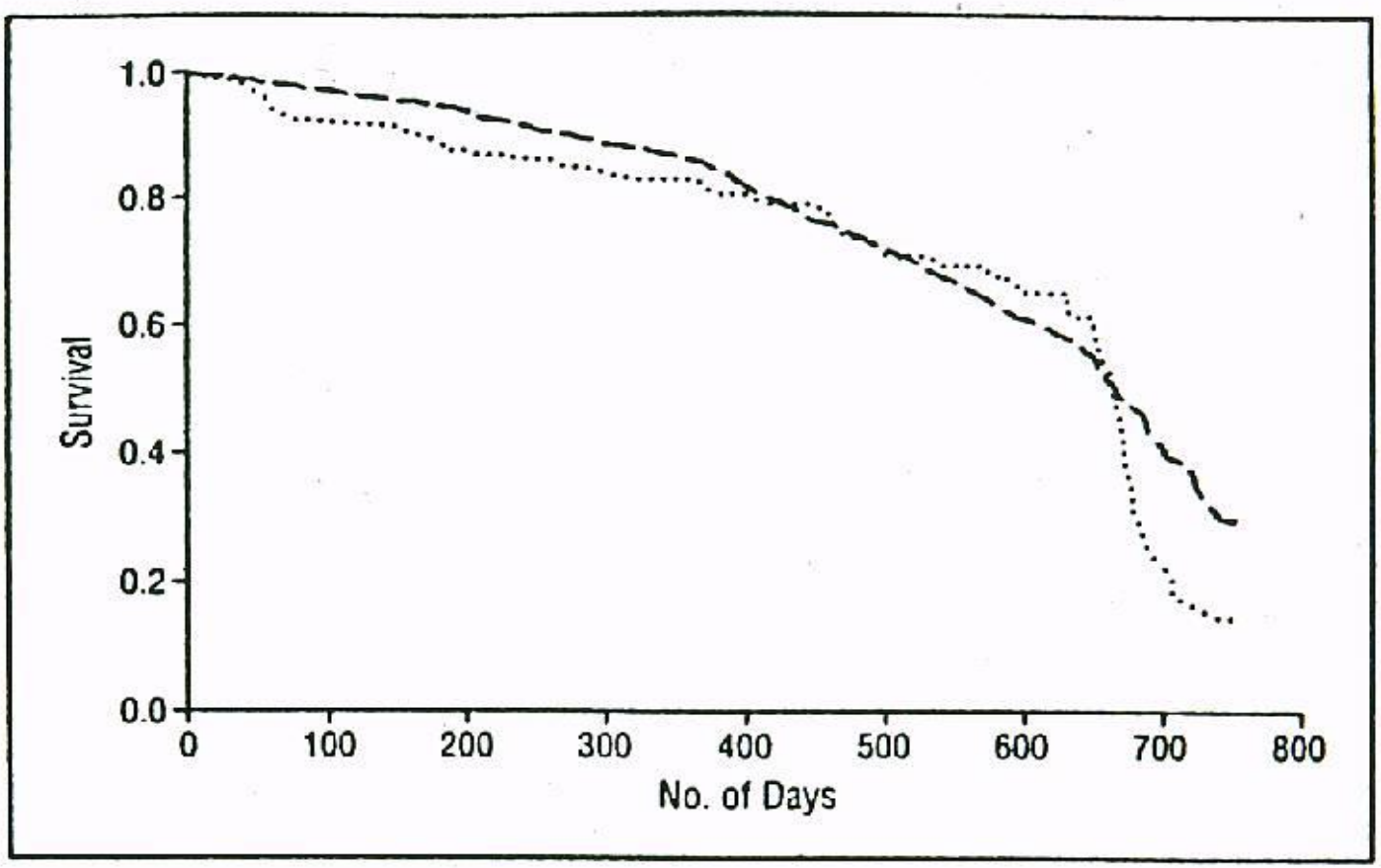
Methods: Participants were 84 cognitively normal men and women (70% response rate), 65 years and older, from a variety of urban and suburban settings, including private homes, assisted-living apartments, transitional care facilities, and nursing homes. In-person interviews were conducted with each participant to obtain information about demographic characteristics, life and health, and desire for various life-sustaining procedures for 4 hypothesized levels of dementia.

Results: Approximately three fourths of participants said they would not want cardiopulmonary resuscitation, use of a respirator, or parenteral or enteral tube nutrition with the milder forms of dementia, and 95% or more of participants would not want these procedures with severe dementia. In addition, only one third or fewer participants thought they would want to be hospitalized or given antibiotics if they were severely demented. Logistic regression analysis showed a relationship between participants' desire for life-sustaining procedures and having less education, greater independence, and a higher perceived quality of life.

Conclusions: Most surveyed individuals did not desire life-sustaining treatments with any degree of dementia, and the proportion of individuals not desiring such treatments increased with the projected severity of dementia. These findings indicate a need for including dementia in advance directives planning.

Arch Fam Med. 1999;8:421-425

Recommend Diplomatically Against PEGs: Compassion



A 24-month survival comparison of residents with severe cognitive impairment with (dotted line) and without (dashed line) feeding tubes.

Tube Feeding in Patients With Advanced Dementia

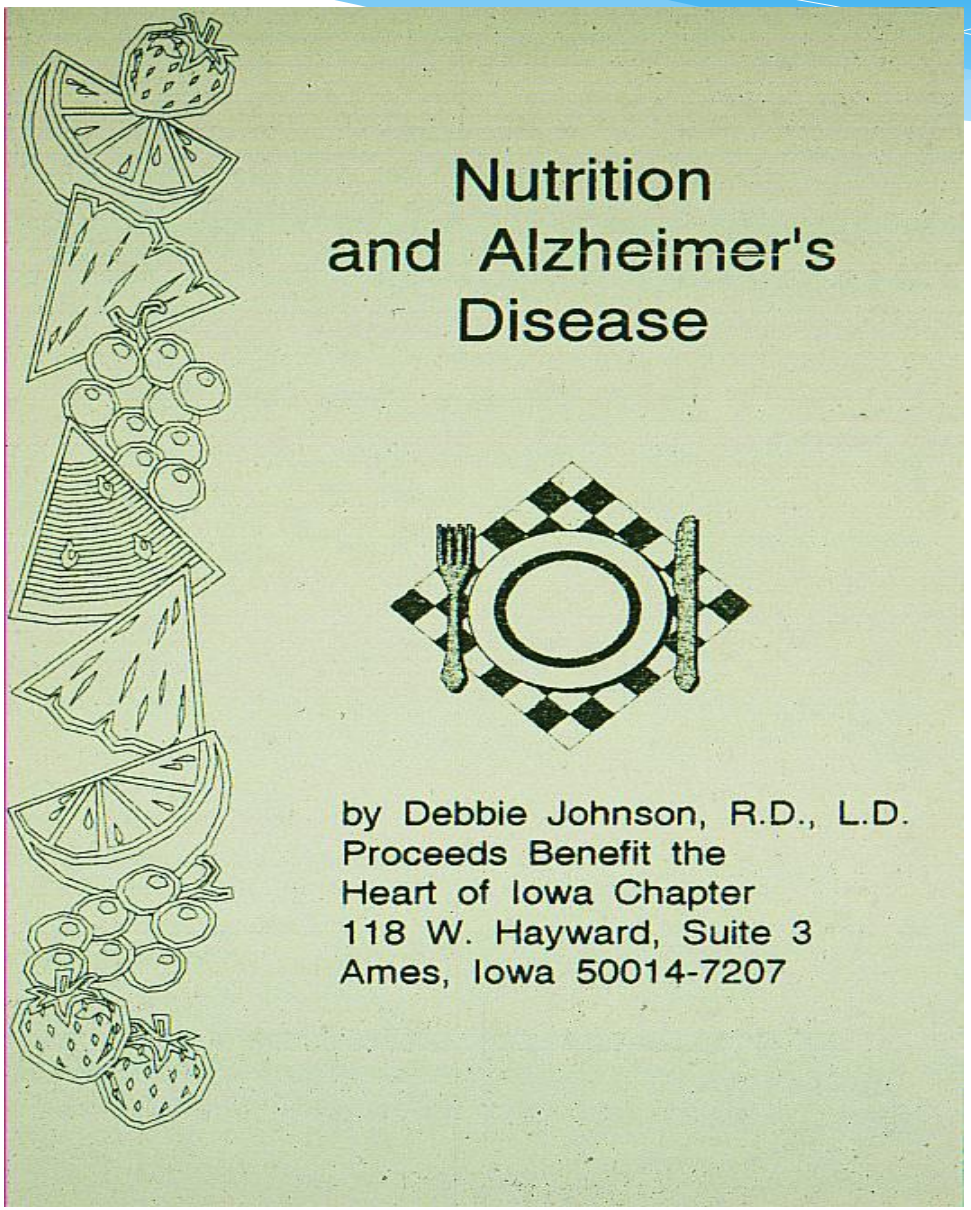
A Review of the Evidence

Thomas E. Finucane, MD
Colleen Christmas, MD
Kathy Travis, MD

Patients with advanced dementia frequently develop eating difficulties and weight loss. Enteral feeding tubes are often used in this situation, yet benefits and risks of this therapy are unclear. We searched MEDLINE, 1966 through March 1999, to identify data about whether tube feeding in patients with advanced dementia can prevent aspiration pneumonia, prolong survival, reduce the risk of pressure sores or infections, improve function, or provide palliation. We found no published randomized trials that compare tube feeding with oral feeding. We found no data to suggest that tube feeding improves any of these clinically important outcomes and some data to suggest that it does not. Further, risks are substantial. The widespread practice of tube feeding should be carefully reconsidered, and we believe that for severely demented patients the practice should be discouraged on clinical grounds.

JAMA. 1999;282:1365-1370 www.jama.com

PATIENTS WITH ADVANCED DEmentia commonly develop difficulty eating, often when they become bedridden and dependent in all activities of daily living. They may resist or be indifferent to food, fail to manage the food bolus properly once it is in the mouth (oral phase dysphagia), or aspirate when swallowing (pharyngeal phase dysphagia). Enteral tube feeding is intended to prevent aspira-


Nutrition
and Alzheimer's
Disease
by Debbie Johnson, R.D., L.D.
Proceeds Benefit the
Heart of Iowa Chapter
118 W. Hayward, Suite 3
Ames, Iowa 50014-7207

Recipes

When it is difficult to get the patient to eat enough, make every bite count. These are some ideas - be creative.

Juicy Gelatin

1 package gelatin
1 cup hot water
1 cup fruit juice

Prepare jello as usual except substitute juice for the cold water.

Milky Gelatin

1 package gelatin
1 cup hot water
1 cup milk

Prepare gelatin as usual except substitute milk for the cold water.

Applesauce Prune Bran

1/2 cup bran
1/2 cup prune juice
1/2 cup applesauce

Mix together and serve 2 tablespoons with each meal. (Do not give to patients with poor intake of fluids.)

PAS: Exclusionary Policies?

* Oregon and elsewhere PAS designed for terminal cancer and also fits ALS, but not AD. Why?
* Netherlands and Switzerland have no six-month rule, so AD fits and about 10 percent use it, generally secobarbital or pentobarbital (as many as 70+pills mixed in a shake), on the basis of entlustering
* In the US, although it is illegal, pre-emptive assisted suicide occurs in AD without the prescribing doctor present (usually peaceful, family, no grandkids, Bach).
* Janet Atkins and Dr. K in Flint
* Suicide Tourism – Mr. Vine the Sa Fran clown who loved alone and flew to Switzerland in 2019 for *DIGNITAS*

Mr. Vine

Special Issue: Research Ethics in Empirical Ethics Studies: Case Studies and Commentaries

Commentary 2: Two Roads Diverge: Assisted Suicide in Alzheimer's Disease for a Research Participant

Journal of Empirical Research on Human Research Ethics
2019, Vol. 14(5) 490–492

DOI: 10.1177/1556264619853198b
journals.sagepub.com/home/jre
SAGE

Stephen G. Post[1]

Mr. Vine is sad about his plight, as anyone would have reason to be. Sadness has its reasons, while depression has none, and the two are not the same. The path to a better future calls Mr. Vine to Switzerland unless his external circumstances and support can be improved, and the primary researcher involved on the team (Dr. Portacolone) has taken a number of steps toward this goal. But even if circumstances are elevated, it is the indignity of living and dying with dementia that Mr. Vine wishes to avoid.

Two roads diverge. "Deeply forgetful people" (Post, 2000) can and do live on in dignity with varying degrees of continuing self-identity. Every case is different, and Alzheimer's disease (AD) is increasingly referred to of late as a "spectrum disorder" (Devi, 2017) for which many psychosocial interventions can bring surprising benefits, such as personalized music (see www.musicandmemory.org). But people are biased against this path due to "hypercognitive" values (Post, 1995), which obscure the ways in which self-identity can be expressed despite dementia, and relies on valuing lives too exclusively on the basis of the "procedural rationality" of *what we do* (proposed future goals and their implementation as "agents") rather than on the basis of the "symbolic rationality" of *who we are* (the core of self- identity) that can be well stimulated with creative personal care. Mr. Vine seems to prefer to die pre-emptively via suicide while his procedural memory and agency are still sufficiently intact for him to propose suicide and operationalize it with some assistance.

Mr. Vine, however, remains open-minded to psychosocial interventions as suggested by his caring "live alone" investigator who has engaged him in meaningful interactions as a subject. Yet Mr. Vine appears serious about assisted suicide via a flight to the *DIGNITAS* center near Zurich, where assisted suicide is available for a price as can be observed on the web.

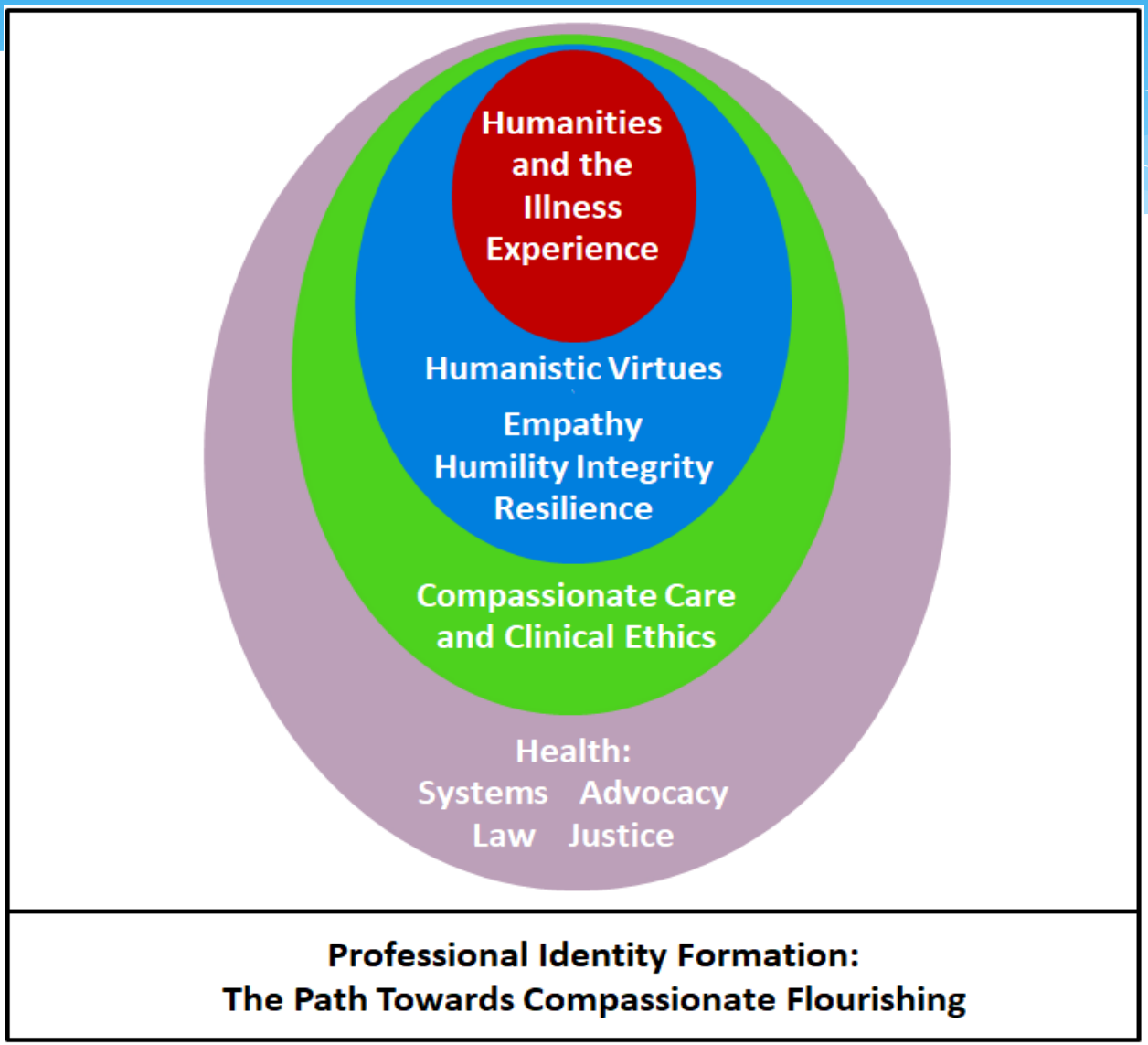
Mr. Vine seems to be able to pay the US$12,000 needed for physician-assisted suicide (PAS) in Switzerland and therefore can implement his wishes when people who are poor could not. Does this make his plan any less worthy of moral support? Is it right that autonomy in this case is related to relative wealth?

aged when significant decline is imminent, just as they condemned it in the young as lacking in courage. The Dutch are in step with the ancients when they justify AD PAS (physician-assisted suicide) as an alternative to "self-effacement" even though AD is not a "terminal condition" in the imminent sense, although in the broadest sense it is terminal and the Alzheimer's Association describes it as such. For those who hold "hypercognitive values," AD is metaphorically terminal in a cognitive sense (de Beaufort & van de Vathorst, 2016). Perhaps Mr. Vine feels this way, and he is not alone in this today or historically. Yet to respect his interest in PAS is also to diminish the gravitas of the disability perspective that cognitive deficits are not the end of a life worth living, and that we should embrace the deeply forgetful as "differently abled." Indeed, perhaps the researcher involved with Mr. Vine is an advocate for this inclusive view, and we have to ask where his or her conscience should be considered.

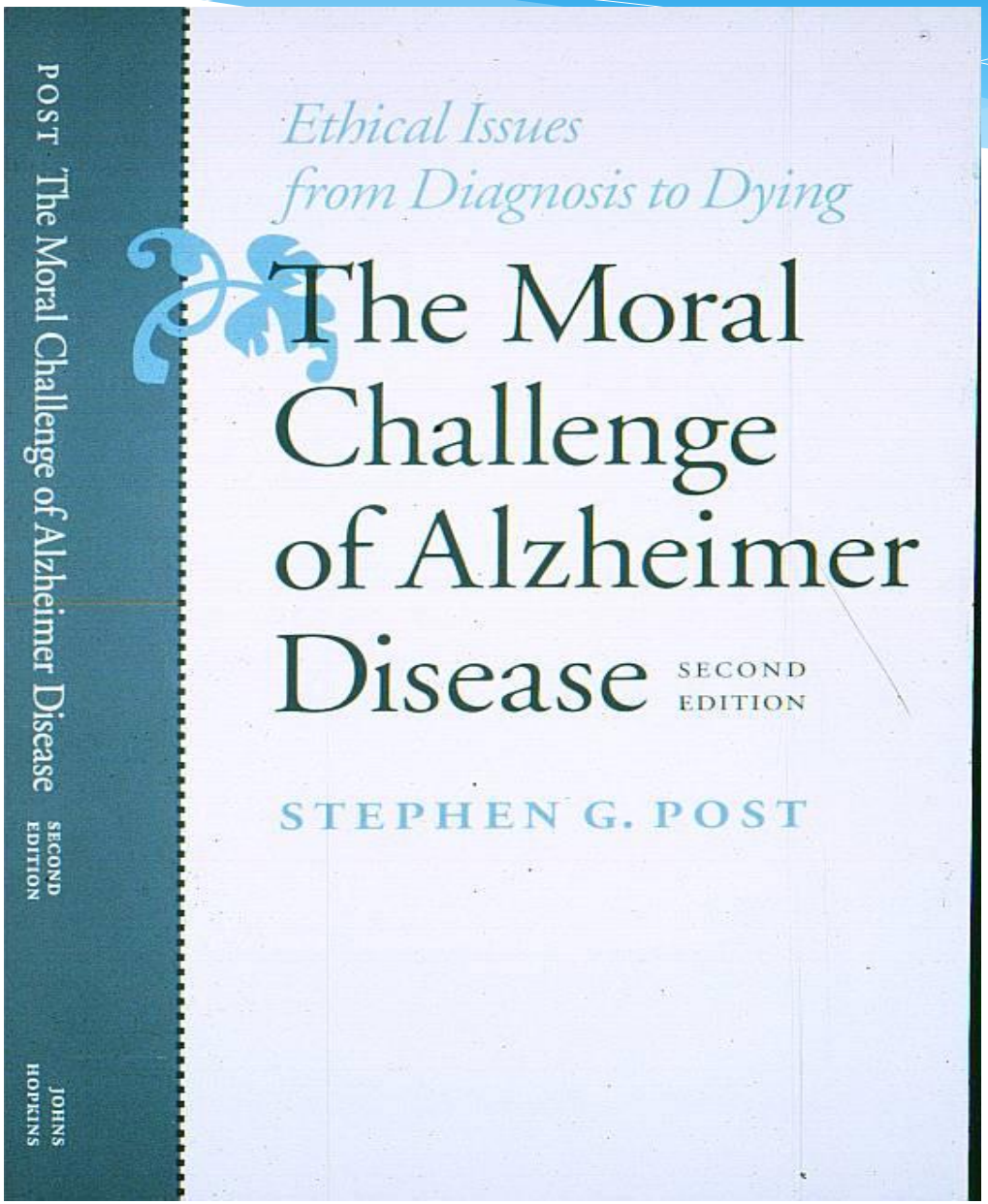
In the Netherlands only about 5% of those diagnosed with AD take the path of PAS, even though that nation has what is probably the finest publicly funded long-term care system in the world, including entire parks with state-of-the-art design, wonderful dementia guide dogs, beautiful pathways, and so forth. The 5% are not being forced into AD PAS as a default option. They really do have two paths, both equally supported. Perhaps the relatively low figure of 5% is an artifact of people with progressive dementia forgetting that they desired to pursue PAS (e.g., in the movie *Still Alice*), but perhaps they come to see that a deeply forgetful life is the only life they've got (Dresser, 2017). A very few people with AD are actually euthanized in the Netherlands, and only they have an advanced directive stating that this is what they wish at a certain level of decline. But this is rare because doctors in the Netherlands are generally against killing (Tomlinson & Stott, 2015).

For those who support AD PAS, it seems plausible to assert that *wherever PAS is legal for individuals who are competent to act and are within six months of death, it should also be made legal for people with an early diagnosis of*

Our Center Model




JONATHAN SWIFT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