



DIGNITY FOR DEEPLY FORGETFUL PEOPLE: They are so much more than society perceives them to be

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DUKE July 5 2022



METAPHYSICS & DIGNITY



“I maintain that the human mystery is incredibly demeaned by scientific reductionism, with its claim in promissory materialism to account eventually for all of the spiritual world in terms of patterns of neuronal activity. This belief must be classed as a superstition. ... We have to recognize that we are spiritual beings with souls existing in a spiritual world as well as material beings with bodies and brains existing in a material world.”

~ JOHN ECCLES



Still There? Akashic Records



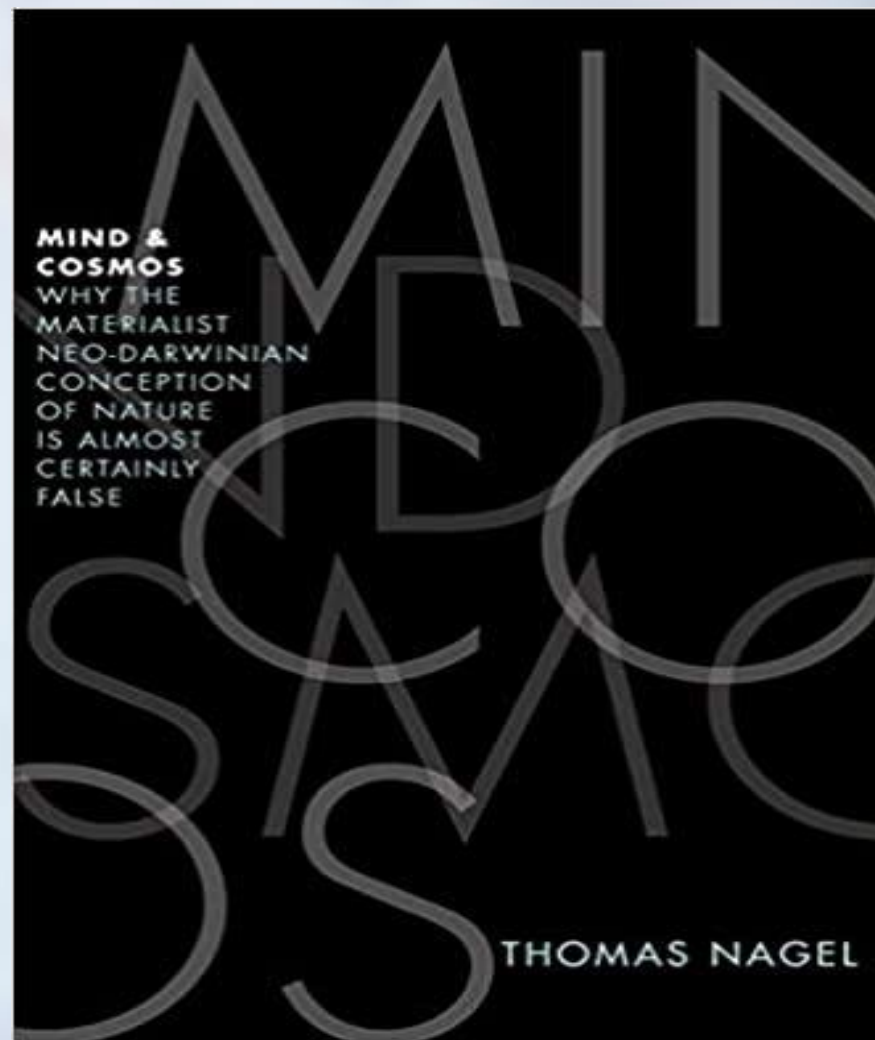


Consciousness (SGP 1995): Indian Institute for Advanced Studies, Bangalore 2015





What Is Mind? Nagel, *Mind & Cosmos*





Dignity: To Hold in Grace

- "THE QUALITY OF BEING WORTHY OF HONOR AND RESPECT"
- Namaste in Mt. Vernon, Ohio
- One Mind
- Something more than "glorified pond scum"



THE SYMBOLS OF SPIRIT

- "It is through symbols that man consciously or unconsciously lives, works and has his being."
~Thomas Carlyle
- "Symbols are powerful because they are the visible signs of invisible realities." ~Augustine



We Live in Symbols and They in Us

- Janet Keck,
- “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
- Pastoral care is largely based on symbols



DIGNITY

for deeply forgetful people

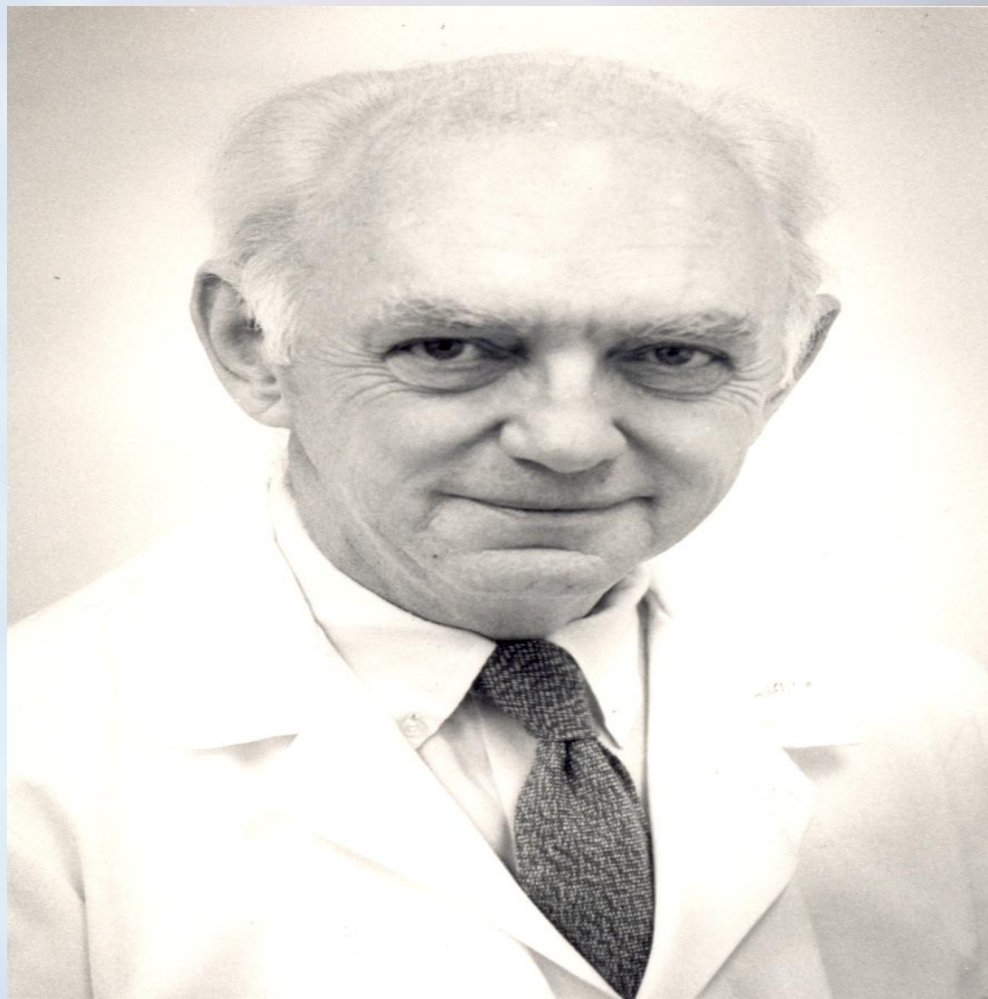
How Caregivers Can Meet the
Challenges of Alzheimer's Disease

STEPHEN G. POST

with a Caregiver Resilience Program by
Rev. Dr. Jade C. Angelica



Jim's Twig at Heather Hill





THINGS TO DO

- 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?





- 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>



"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



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



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.





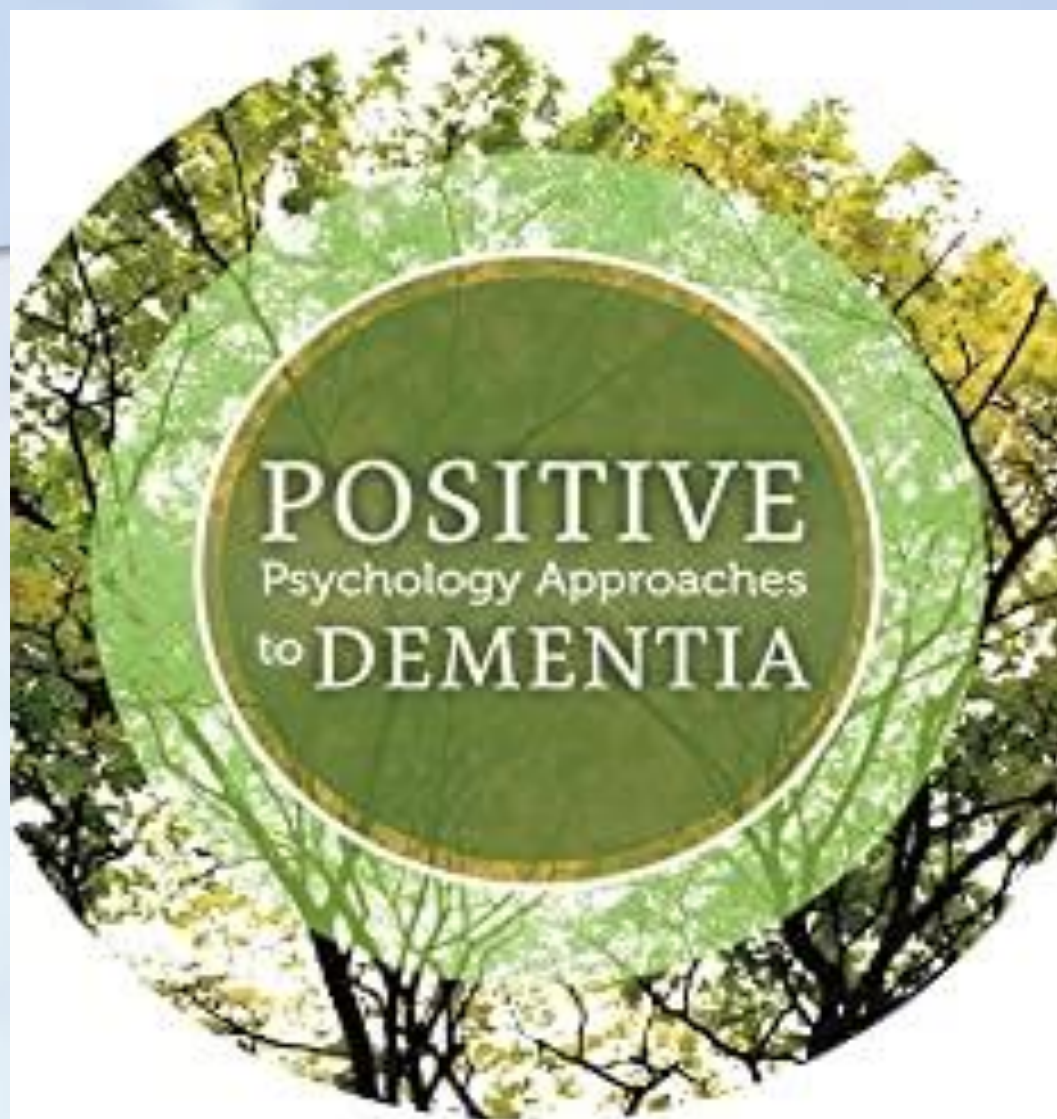
Tactile & Relational: Dogs to the Rescue





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)



Edited by CHRIS CLARKE
and EMMA WOLVERSON

Foreword by Christine Bryden

Hope & Love p. 143

- Hope = “being open to surprises and noticing them”





THE CLASSIC VIEW: **"CLOUD MEMORY?"**

- Henri Bergson, "Matter and Memory: An Essay on the Relation of Body and Spirit" (1896)
- Tolkien, Emerson, Eliot, Buddha, Gandhi, Jung, Wilbur, Huxley, Dossey, Nasr, Campbell, Plato, St. Paul, Eccles
- NAMASTE in Mt. Vernon



'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.”
- Same facts, different Metaphysics?



- “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.



Simon Y Berkovich-GWU 1993

- Speculated a model of the brain as the local computer terminal connecting to some larger informational system



T.F. Brady-UCSD 2008

- Visual memory is so massive as to “pose a challenge to neural models of memory storage and retrieval, which must be able to account for such a large and detailed storage capacity.”
- (Brady et al., Visual Long-Term Memory Has a Massive Storage Capacity for Object Details,” *PNAS* 2008, 105: 14325-9.)



Donald R. Forsdyke-Queens 2015

- Studies show intelligent adults with fine memory but no more than 5% of normal brain tissue having been cured of hydrocephaly as children. He gives us 3 models:



- “Standard model” that long-term memory is held in the brain in some chemical or physical form
- Long-term memory held in the brain in some “minute, subatomic form” as yet unknown
- “Information relating to long-term memory is held outside the brain.”
This option has been with us 20 yrs.

TE Forsdyke, “Wittegenstein’s Certainty is Uncertain: Brain Scans of Cured Hydrocephalics Challenge Cherished Assumptions” *Biological Theory* 2015: 10: 336-342.



Beyond Physicalism

TOWARD RECONCILIATION OF
SCIENCE AND SPIRITUALITY

Edited by

EDWARD F. KELLY,
ADAM CRABTREE, and
PAUL MARSHALL



THE ETHICS OF LANGUAGE: **Why “Deeply Forgetful People”?**

- Inclusive
- Respectful
- Consciousness (Bangalore)
- Continuity of Self
- Noticing identity & purpose” (a road for my daughter)
- “Dementia” is a “syndrome” with Mny disease causes



Dangerous “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 utilitarian eugenics
- Dr. Leo Alexander (“voluntary associations”)
- October 1939 Hitler’s euthanasia note



Exclusion by Negative Metaphors

- “husk”
- “gone”
- “empty”
- “shell”
- “useless eaters”
- Rev. Martin Luther King Jr “Language open up the beloved community”



Jonathan Swift's *Gulliver's Travels* 1726 vs. Francis Bacon's *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."



The Injustice of Leftovers

- Est. 5 million Americans live with probable AD, often a “mixed diagnosis”
- 3% at age 65, doubles every five years, est. 18% at age 80 (60% + women age 95 to 100)
- The estimated incidence of Alzheimer’s is notably higher in Blacks (2 to 1) and Hispanics (1.5 to 1) than in Caucasians
<https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>
- The U.S. policy of spend down contrasts with Canada, Switzerland, the Netherlands, etc.



The New England Journal of Medicine

Copyright, 1949, by the Massachusetts Medical Society

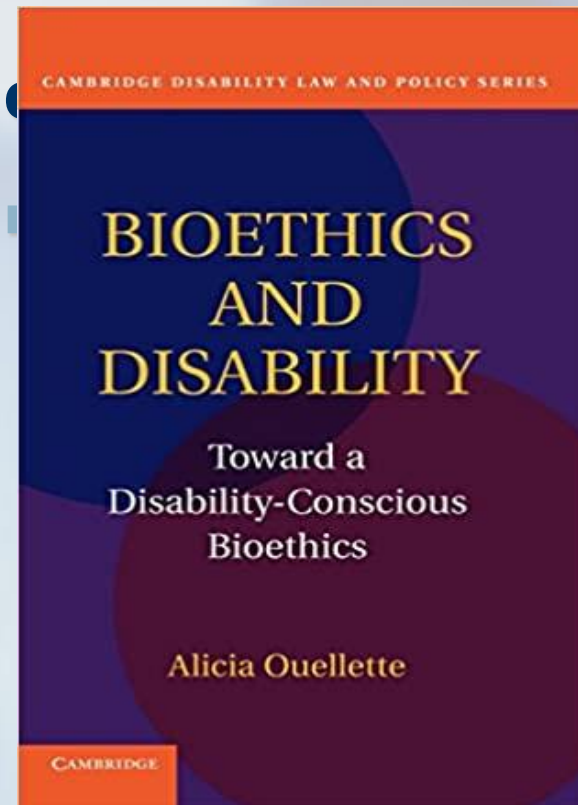
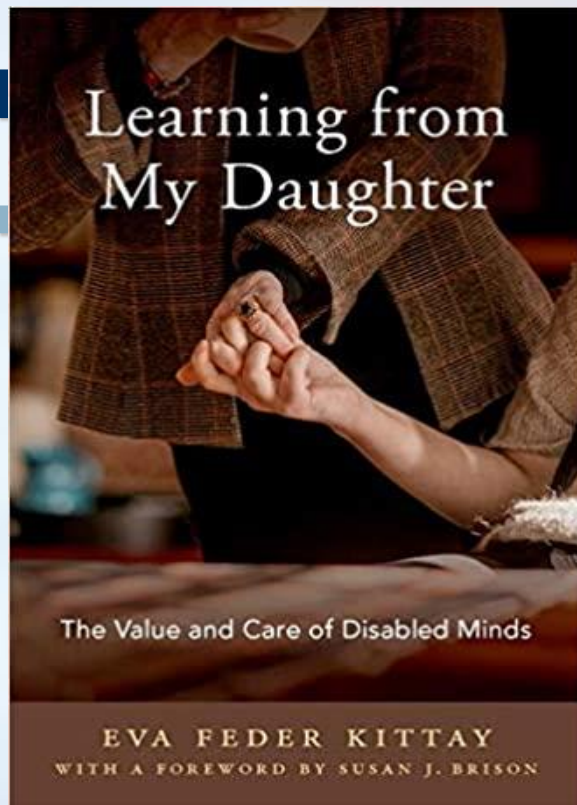
JULY 14, 1949

MEDICAL SCIENCE UNDER DICTATORSHIP

LEO ALEXANDER, M.D.*

BOSTON

Disability Advocates / Bioethics





PREVENTION

- Mediterranean Diet/greens and fruits
- Walking
- Cognitive stimulation
- Social and intellectual engagement
- Sleep
- Meditation to destress (Dharma S Khalsa MD) www.alzheimersprevention.org
- MusicandMemory.org
- A good multi-vitamin



Who is Destined for Alzheimer's Disease? 50 million world wide now to 150 million by 2050

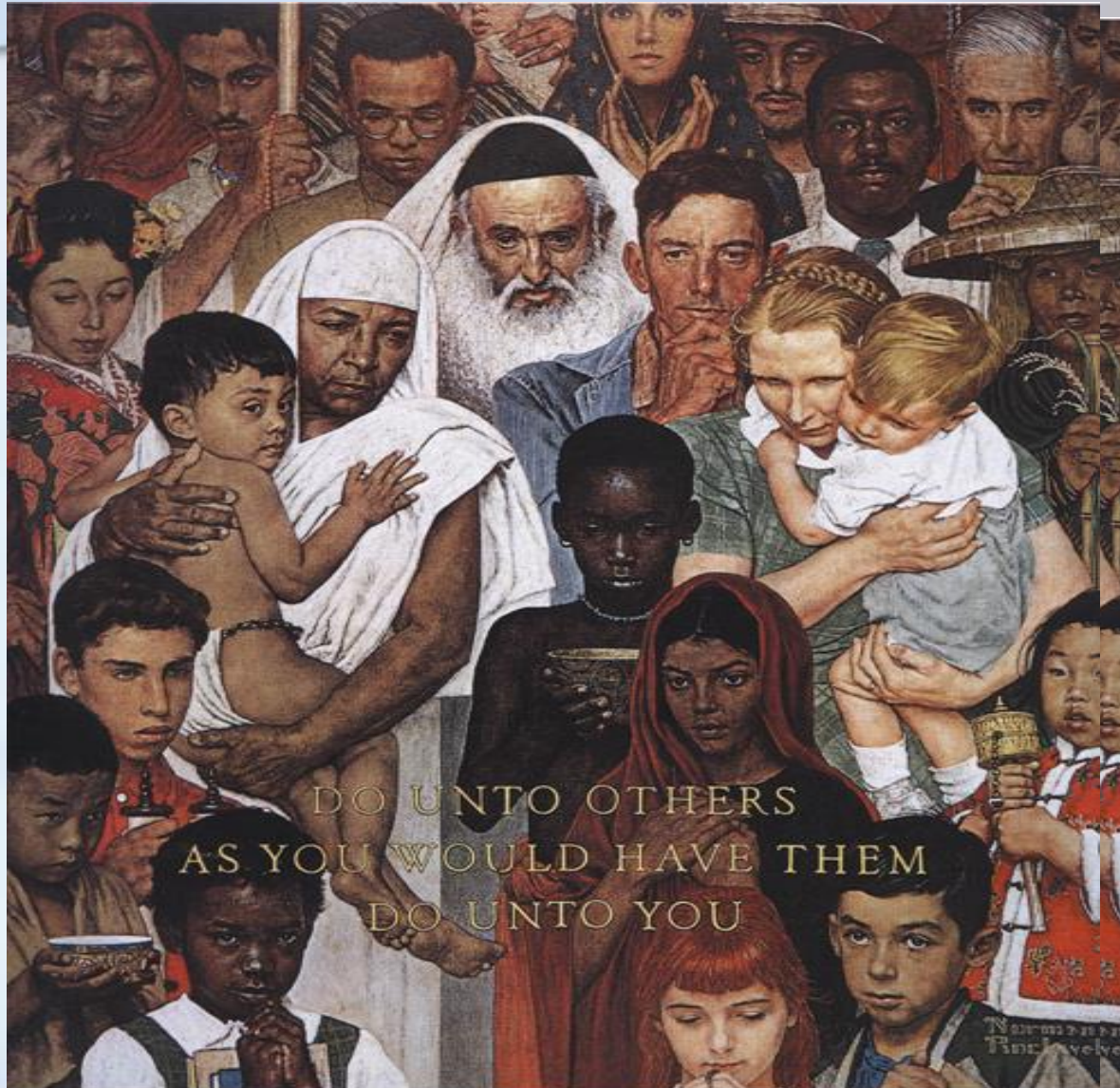
- Margaret Lock, *The Alzheimer Conundrum: Entanglements of Dementia and Aging* (2015)
- Rates have gone down due to public health (e.g., diet, lead removal, education,
- The Lancet Commission on Dementia Prevention (2017/2020): modifiable risk factors include head injuries in mid-life, excessive alcohol consumption, air pollution in later life, sedentary life style, etc.)
- JAMA Social Determinants of Dementia significant: associations with income, education, housing, employment, nutrition, neighborhoods



United Healthcare & Volunteer Match

- 41% VOLUNTEERED IN 2009 ABOUT 100 HOURS/YEAR
- **89%** agreed that “volunteering improved my sense of well-being”
- **73%** “lowered my stress levels” (serenity)
- **92%** “enriched sense of purpose in life”
- **68%** “made me physically healthier”
- **77%** “improves emotional health”
- **78%** “helps recovery from loss and disappointment”
- Improved sleeping, friendships; reduced anxiety & helplessness, **25% volunteer through their workplace, and 76% of them feel better about employer as a result**
- www.volunteermatch.org & United Healthcare

Breathe Deep and Notice Rockwell's *The Golden Rule*





Purpose and Kindness

- 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 Pathologic Changes on Cognitive Function in Advanced Age," *Archives of General Psychiatry*, Vol. 69 (no. 5), 2012, pp. 499-504)
- Usually associated with helping others in a meaningful way that floats your boat
- "The meaning of life is to find your gift. The purpose of life is to give it away."
(Shakespeare & Picasso)



Preventing Hypertension

- 1100 older adults ages 51 to 91 were interviewed and had BP checks in 2006
- Those subjects who were volunteering at least 200 hours (est. four hours per week) in the past year at the time of their first interview were 40% less likely to have developed hypertension four years later compared to nonvolunteers

(Sneed, et al., “A prospective study of volunteers and hypertension risk in older adults,” *Psychology & Aging*, Vol. 28, 2013, pp. 578-586)



"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

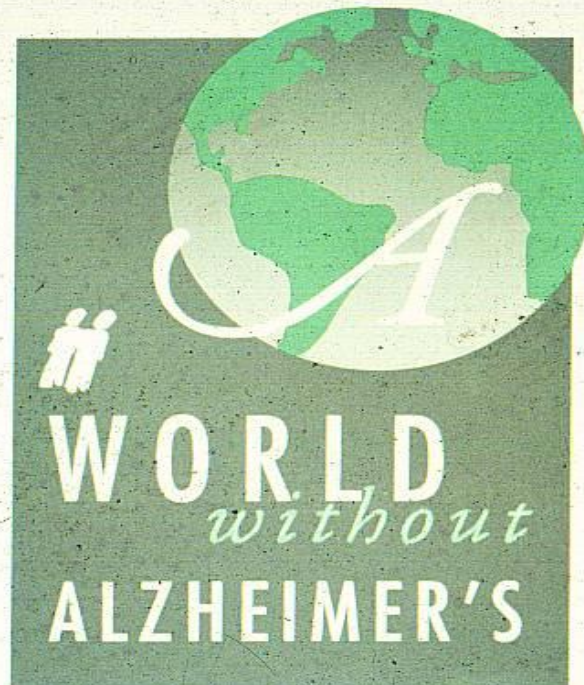


PHARMA?

- 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 approved a few months later.
- 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 other NSAIDs, *Ginkgo Biloba*, ...possible vitamin D perhaps.



See the future and help make it happen!



● NEW EXECUTIVE DIRECTORS ORIENTATION ●

October 30 - 1996

● ALZHEIMER'S ASSOCIATION ANNUAL MEETING ●

October 31 - November 2, 1996

● BOARD & COMMITTEE MEETINGS ●

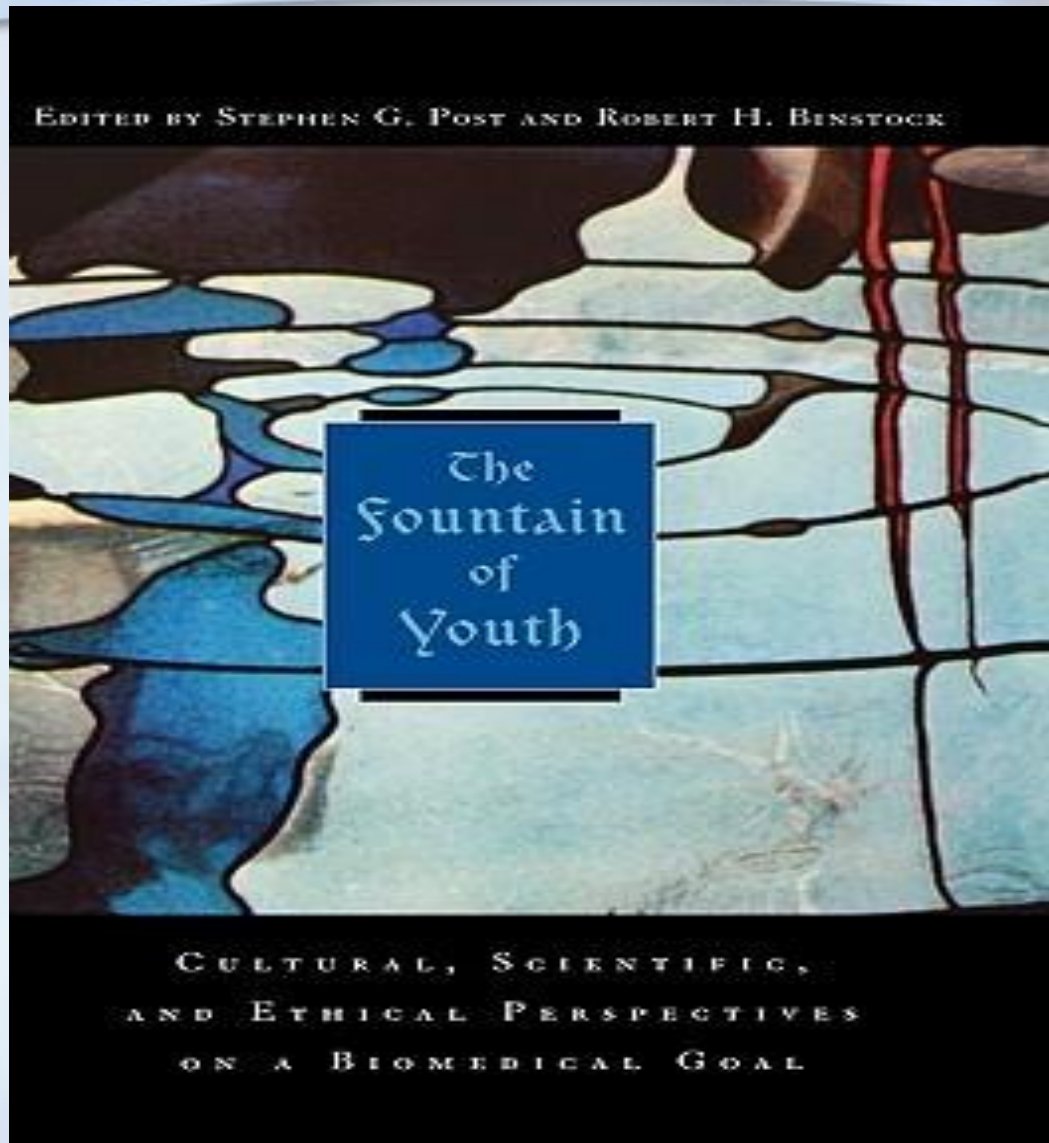
November 2 - 4, 1996

Chicago Marriott O'Hare - Chicago, IL

ALZHEIMER'S
ASSOCIATION



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





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



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 par-

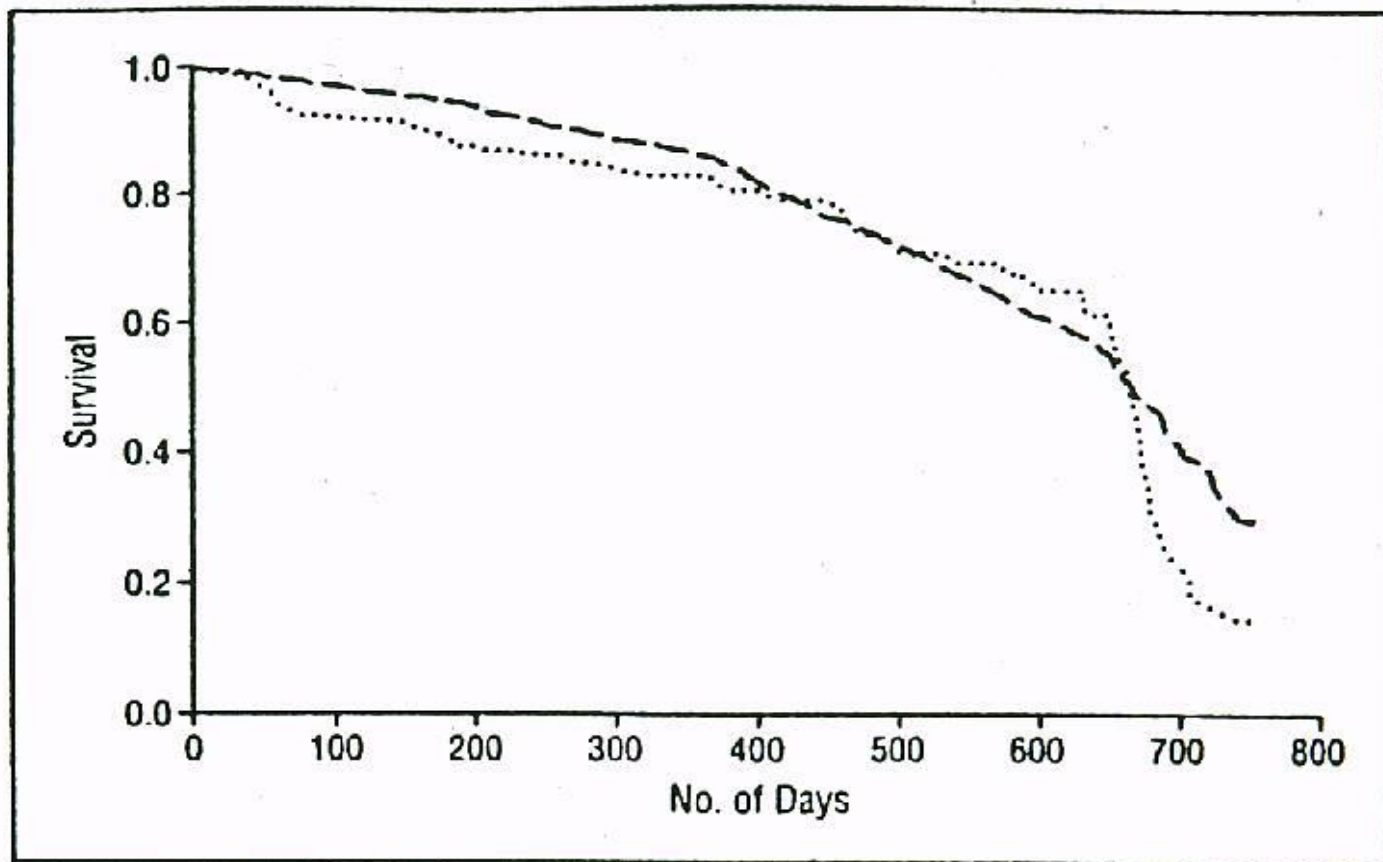
ticipants would not want these procedures with severe dementia. In addition, only one third or fewer participants thought they would want to be hospitalized or given antibiotics if they were severely demented. Logistic regression analysis showed a relationship between participants' desire for life-sustaining 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



PEGs?



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

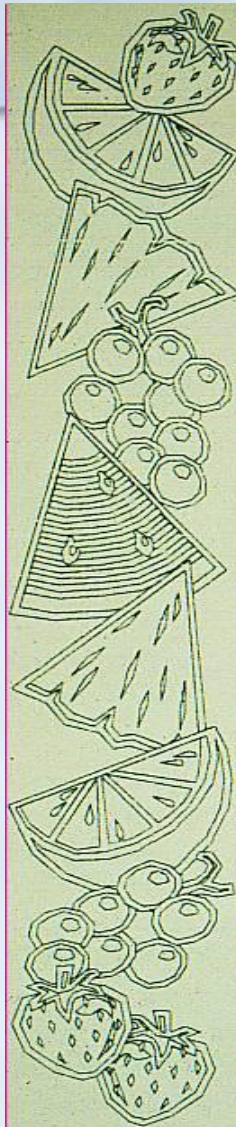
Kathy Travis, MD

PATIENTS WITH ADVANCED DEMENTIA 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-

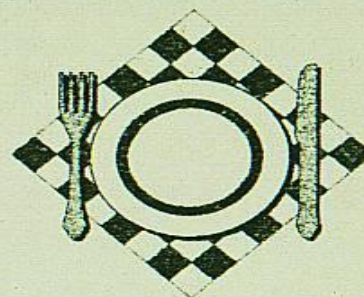
Patients with advanced dementia frequently develop eating difficulties and weight loss. Enteral feeding tubes are often used in this situation, yet benefits and risks of this therapy are unclear. We searched MEDLINE, 1966 through March 1999, to identify data about whether tube feeding in patients with 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



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.)



Look for Pain

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



PAINAD Scale 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)
- Can be used in several minutes



PRE-EMPTIVE ASSISTED SUICIDE

- “Dignitas” in Switzerland
- Quebec & The Netherlands (no 6-month rules)
- Not in the US, but there was Janet Atkins
- Two Psychiatrists in Chicago
- The Shores of Lake Erie

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

Stephen G. Post¹

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*

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¹Stony Brook University Hospital, Health Sciences Center, Stony Brook.



*Ethical Issues
from Diagnosis to Dying*



The Moral Challenge of Alzheimer Disease

SECOND
EDITION

STEPHEN G. POST

POST The Moral Challenge of Alzheimer Disease

SECOND
EDITION

JOHNS
HOPKINS

