



Dementia Training Australia

# Stephen Post

## "Hope and Deeply Forgetful People"

Funded by the Australian Government



# WHY DEEPLY FORGETFUL PEOPLE MATTER: HOPE, ETHICS, AND INDIVIDUALS WITH DEMENTIA

Stephen G. Post

# TIP I. Assume that Grandma's Still There



# 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

- \* I spent three hours yesterday afternoon with my sister and I tried to make sure that every facial expression, the tone of my voice, the intentionality of my focus was positive and loving. I didn't understand a word she said but it didn't matter. I felt love by being loving and Wendy felt love by receiving my love. At the end of our visit she said "I want you to stay with me always."

**Cathy Chapin**, *Community Relations & Program Support*, W. London, ON

## Vignette 3

\* It was in his last moments that my mother seemed to be rewarded for all her hard work. My grandfather looked at my mother and spoke to her with completely lucidity for the first time in a year. He talked about the old times when he used to walk her to school. Then he talked about me and told her to make sure I kept working hard in school. And the last thing he said was how proud he was of her and that he loved her. The next morning he was gone.

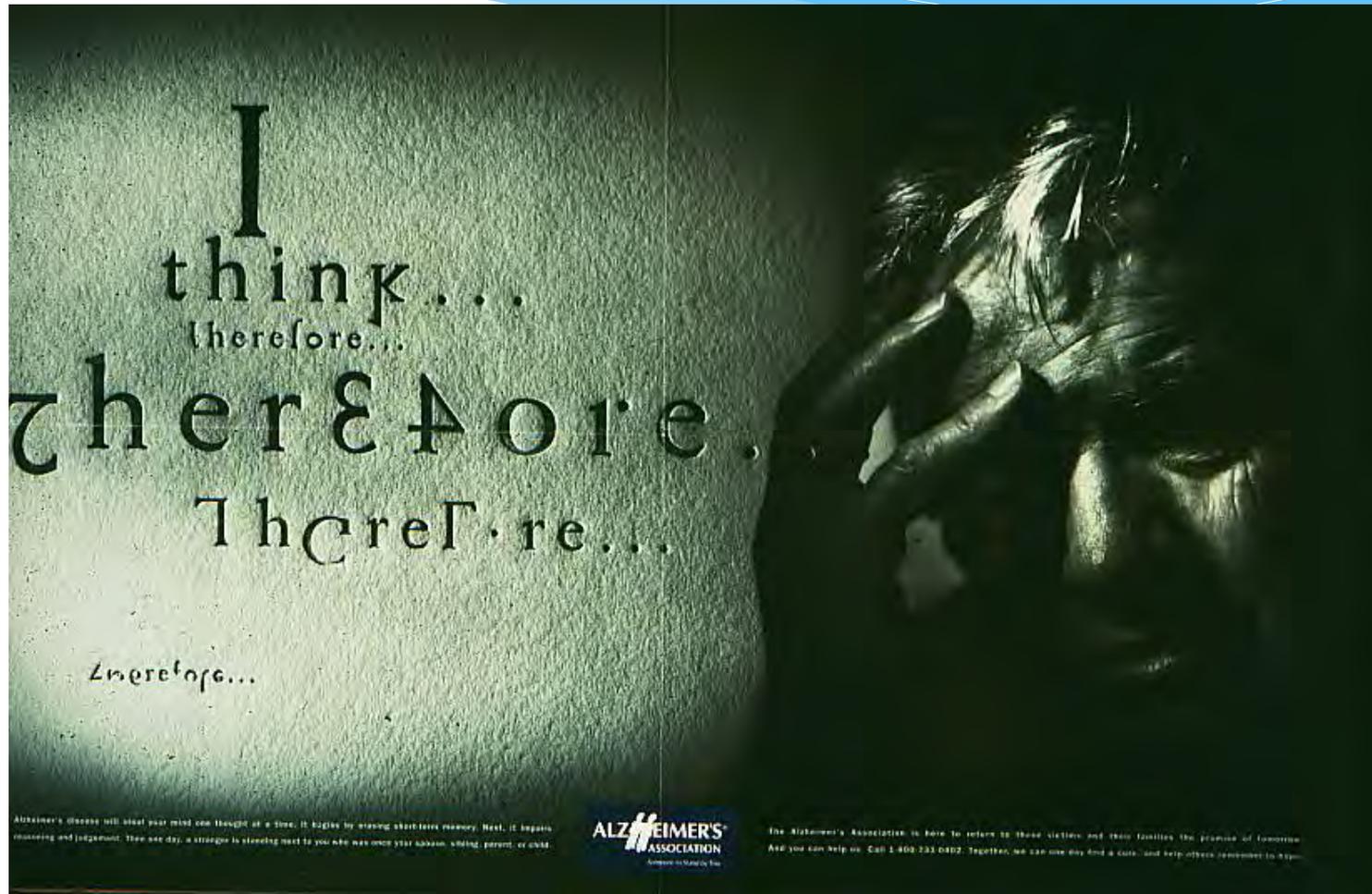
\* A medical student recently (November 2015) described his grandfather's "terminal lucidity" after months of being entirely unable to communicate due to Alzheimer disease.

# Vignette 4

\* 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*.

# TIP II. Avoid “Hypercognitive” Values and Narrow “Personhood” Ideas



I think...  
therefore...  
Therefore.  
Therefore...  
Therefore...

Alzheimer's disease will steal your mind one thought at a time. It begins by erasing short-term memory. Next, it begins erasing and judgment. Then one day, a stranger is standing next to you who was once your spouse, sibling, parent, or child.

**ALZHEIMER'S**  
ASSOCIATION  
America's Memory Care

The Alzheimer's Association is here to refer to those victims and their families the promise of freedom. And you can help us. Call 1-800-273-8402. Together, we can one day find a cure...and help others remember to help.

# DIMENSIONS OF SELF-IDENTITY: Sources of Caregiver Meaning

- \* Creativity
- \* Symbolic Meaning
- \* Emotion
- \* Relationality
- \* Mirth
- \* Somatic s
- \* Music & Rhythm
- \* Beauty
- \* Smell/taste (olfactory)
- \* Spirituality
- \* Touch (tactile)
- \* Cognition
- \* Consciousness

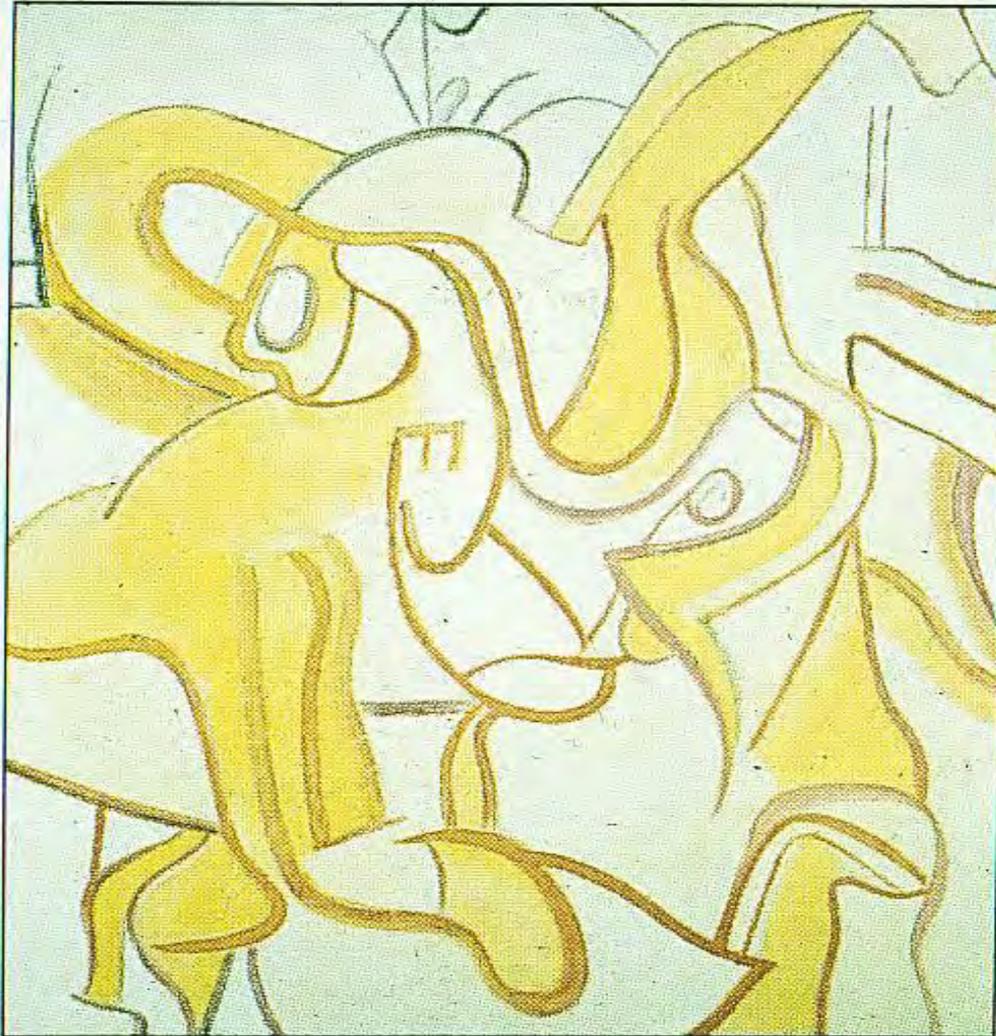
# Creativity: DeKooning



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

**'Untitled' (1987)**

*How much of the artist's hand?*



# Mirth: Joe Foley's Jokes



# Musicandmemory.org

- \* 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)

- \* <http://aging.med.nyu.edu/research/chorus> The Unforgettables
- \* [www.musicandmemory.org](http://www.musicandmemory.org)

# Tactile & Relational: Dogs to the Rescue



# Marvin and Lola

- \* Good afternoon Dr. Post,
- \* I've been taking Lola to Cleveland Clinic Hospital (Florida) to visit patients... Bringing her 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 onto 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](http://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.



# CONSCIOUSNESS: Indian Institute for Advanced Studies, Bangalore 2015



# “Hypercognitive” Values Tiergartenstrasse 4, Berlin

- \* 70,273 in asylums killed in hypothermia research
- \* September 1939-August 1941
- \* About half with “senile dementia”
- \* “Life unworthy of life” “Useless eaters”
- \* Aryans, not Jews or Gypsies
- \* Waterbury, Ct: A case of rape

# Symbolic Rationality: Jim and Cleave

- \* Jim's twig, Cleave's hat
- \* Rationality as a decisional capacity is not morally important. It is rationality as a source of self-identity that matters – i.e., “who” we are rather than “how” we proceed. And in this sense, the deeply forgetful can be surprising.

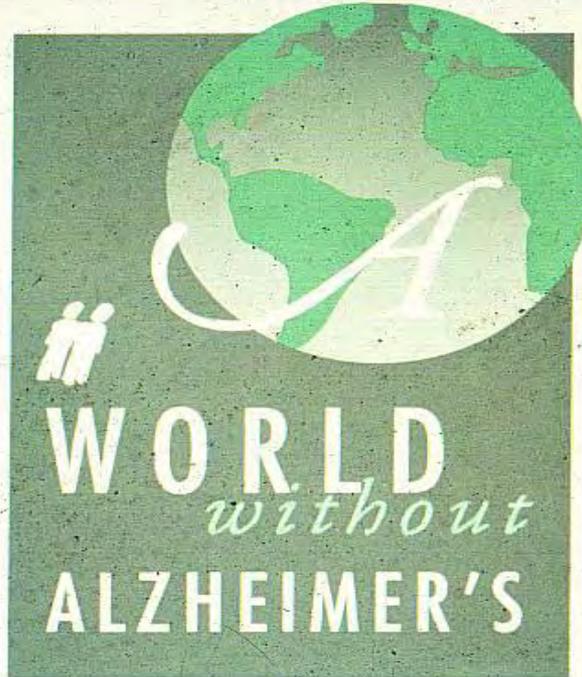
## TIP III. Let's Hope but Not Hype Pharma

- ▶ “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>

# “A .05 Out of 10”

- \* Some patients Rx: cholinesterase inhibitor and glucose antagonist
- \* Almost statistically insignificant, inappropriate for advanced stage
- \* *May delay nursing home placement a bit, and what happens to this logic once placed?*
- \* **Joe Foley: “On a scale of 1 to 10... .05? Music a 9? Poetry a 7?”**

*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

# Failed Preventive Interventions

- \* No impact in presymptomatic use of cholinesterase drugs in people with “MCI” (pre-AD)
- \* *Estrogen replacement* does not delay AD onset in women at higher risk
- \* No benefit shown for use of *ibuprofen* and other NSAIDs, *Ginko Biloba*, etc.

# Rx: Healthy Aging

- \* Diet (fruits, vegetables)
- \* Exercise
- \* Social and intellectual engagement
- \* Walk peacefully with friends to a Greek restaurant and then hit the library to read
- \* Meditation against stress (Dharma Singh Khalsa MD) [www.alzheimersprevention.org](http://www.alzheimersprevention.org)

# HAVE A NOBLE 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 Pathologic Changes on Cognitive Function in Advanced Age,” *Archives of General Psychiatry*, Vol. 69 (no. 5), 2012, pp. 499-504)

# Cicely Saunders: “I can never retire”

Dr. Cicely Saunders (1918-2005)



getting  
**ever older**

de

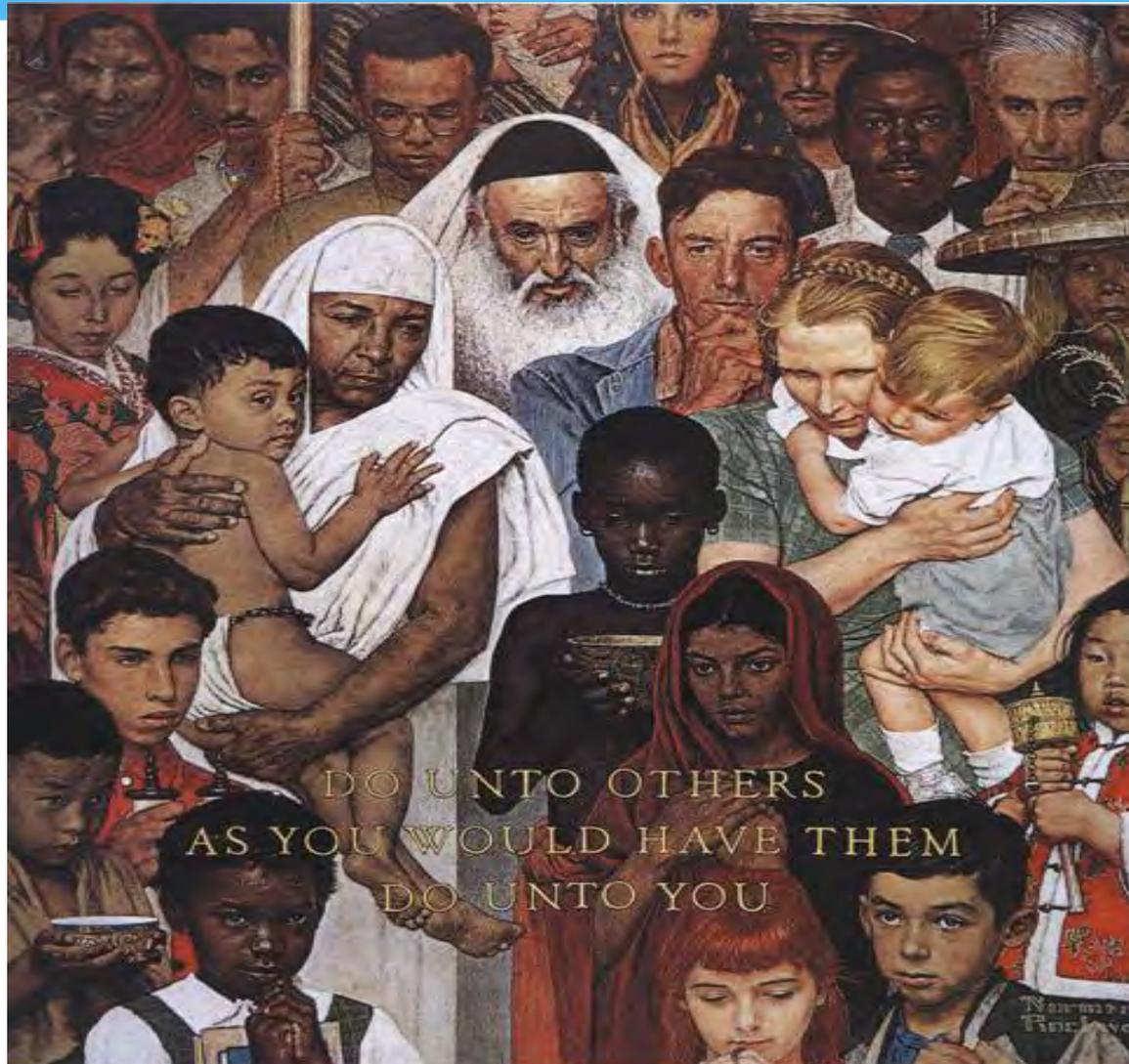
PHOTO: PELLE CARON/AP/WIDE

18 SCIENTIFIC AMERICAN PRESENTS

JEANNE CALMENT  
122 at death

THE QUEST TO BEAT AGING

# TIP IV. Deeply Forgetful People Can Pick Up Empathy in Caregivers



“... talk even to the most cognitively disabled, calling them by name (which, sometimes surprisingly, may come). 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.”

SGPost, “Alzheimer’s & Grace” *First Things* 2004



# The Spirituality of Empathy

- \* Mr. Fred Rogers: “I believe that appreciation is a holy thing – that when we look for what’s best in a person we happen to be with at the moment, we’re doing what God does all the time. So in loving and appreciating our neighbor, we’re participating in something sacred.”

## TIP V: Don't Rule Out the Soul

- \* Are moments of self-identity just bits of brain residue?
- \* Or something more? “You don't have a soul. You are a soul. You have a body.” (C.S. Lewis)
- \* My Hindu friends with their Namaste
- \* Never assume that your consciousness is superior to their consciousness

# TIP VI: Ethical Issues

- ▣ Restrictions on Driving (Leo)
- ▣ Diagnostic Disclosure (Murray)
- ▣ Enrollment in Research (tacrine blood draws)
- ▣ Autosomal Genetic Testing – PS1, PS2 (A Woman from Chicago)
- ▣ Susceptibility Testing (REVEAL APOE-e4)
- ▣ Advance Planning (durable power of attorney for healthcare)
- ▣ Pre-emptive Assisted Suicide (Janet Atkins)
- ▣ Euthanasia by Advanced Directive (Netherlands 2016)
- ▣ Pain!
- ▣ Nutrition & Hydration

## TIP VII: 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)

# Scales for Assessing Pain

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

# TIP VIII: Remind Adult Children

## 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.

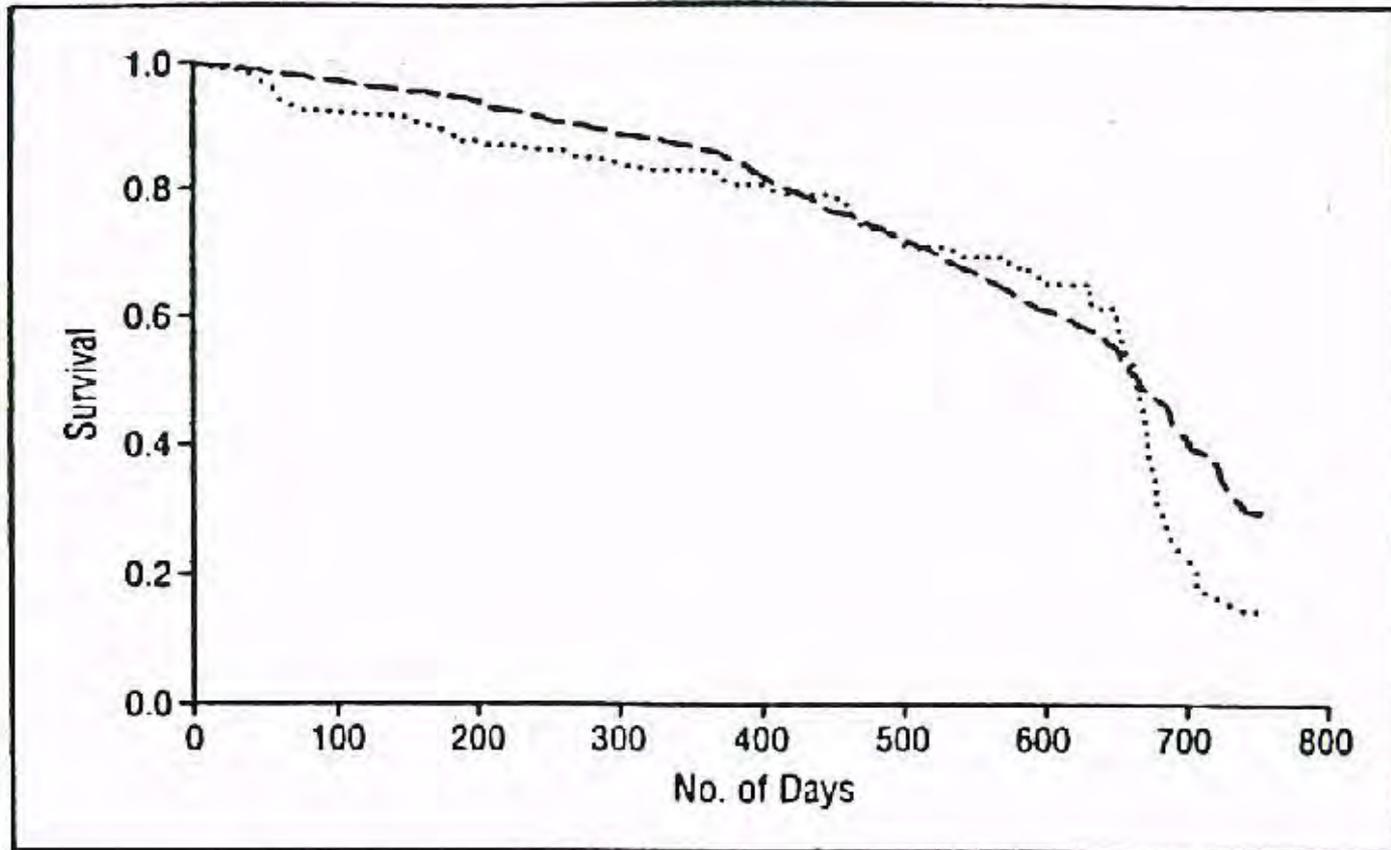
*Arch Fam Med.* 1999;8:421-425

# TIP IX: “Appeal to Compassion in the Face of Suffering”

- \* An abdominal mass
- \* Those blood draws are torturous
- \* Surgery for hip fracture: “His postoperative course is complicated by pneumonia, delirium, and pressure ulcers on his heels and sacrum. He is losing weight and unable to participate in rehabilitation because of his confusion. This is his fourth hospitalization in the past year.”

(Morrison and Meier, “Palliative care,” *NEJM*, Vol. 350, 2004, pp. 2582-2590)

# TIP X: Recommend Against 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

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Thomas E. Finucane, MD

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Colleen Christmas, MD

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Kathy Travis, MD

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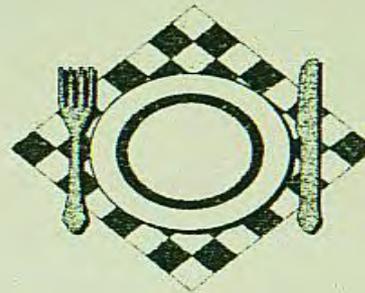
**P**ATIENTS WITH ADVANCED DEMENTIA commonly develop difficulty eating, often when they become bedridden and dependent in all activities of daily living. They may resist or be indifferent to food, fail to manage the food bolus properly once it is in the mouth (oral phase dysphagia), or aspirate when 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.

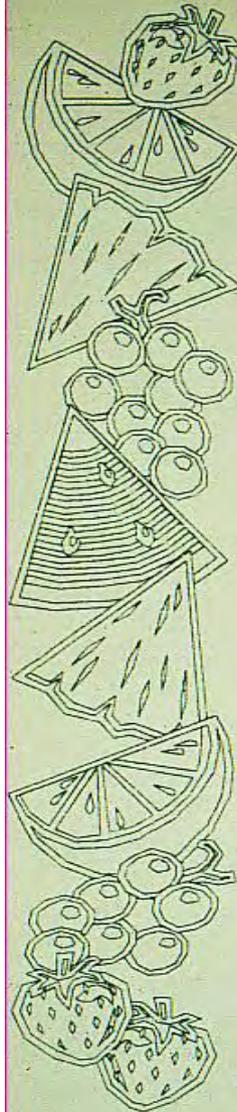
*JAMA.* 1999;282:1365-1370

[www.jama.com](http://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.)

# Music, Memory and Swallowing

- \* Preliminary studies show that “music and memory” intervention improve swallowing
- \* Reduced call for PEGs

# XI. Jonathan Swift

## GULLIVER'S TRAVELS

youngest not above two hundred years old, who were brought to me at several times by some of my friends; but although they were told that I was a great traveller, and had seen all the world, they had not the least curiosity to ask me a question; only desired I would give them *slumskudask*, or a token of remembrance, which is a modest way of begging, to avoid the law that strictly forbids it, because they are provided for by the public, although indeed with a very scanty allowance.

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; so that you may know their age by consulting the registry, which however hath not been kept above a thousand years past, or at least hath been destroyed by time or public disturbances. But the usual way of computing how old they are, is by asking them what kings or great persons they can remember, and then consulting history, for infallibly the last prince in their mind did not begin his reign after they were fourscore years old.

They were the most mortifying sight I ever beheld, and the women more horrible than the men. Besides the usual deformities in extreme old age, they acquired an additional ghastliness in proportion to their number of years, which is not to be described; and among half a dozen, I soon distinguished which was the eldest, although there was not above a century or two between them.

The reader will easily believe, that from what I had heard and seen, my keen appetite for perpetuity of life was much abated. I grew heartily ashamed of the pleasing visions I had formed, and thought no tyrant could invent a death into which I would not run with pleasure from such a life. The King heard of all that had passed between me and my friends upon this occasion, and rallied me very pleasantly, wishing I would send a couple of *struldbrugs* to my own country, to arm our people against the fear of death; but this it seems is forbidden by the fundamental laws of the kingdom, or else I should have been well content with the trouble and expense of transporting them.

I could not but agree that the laws of this kingdom, relating to



# 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.

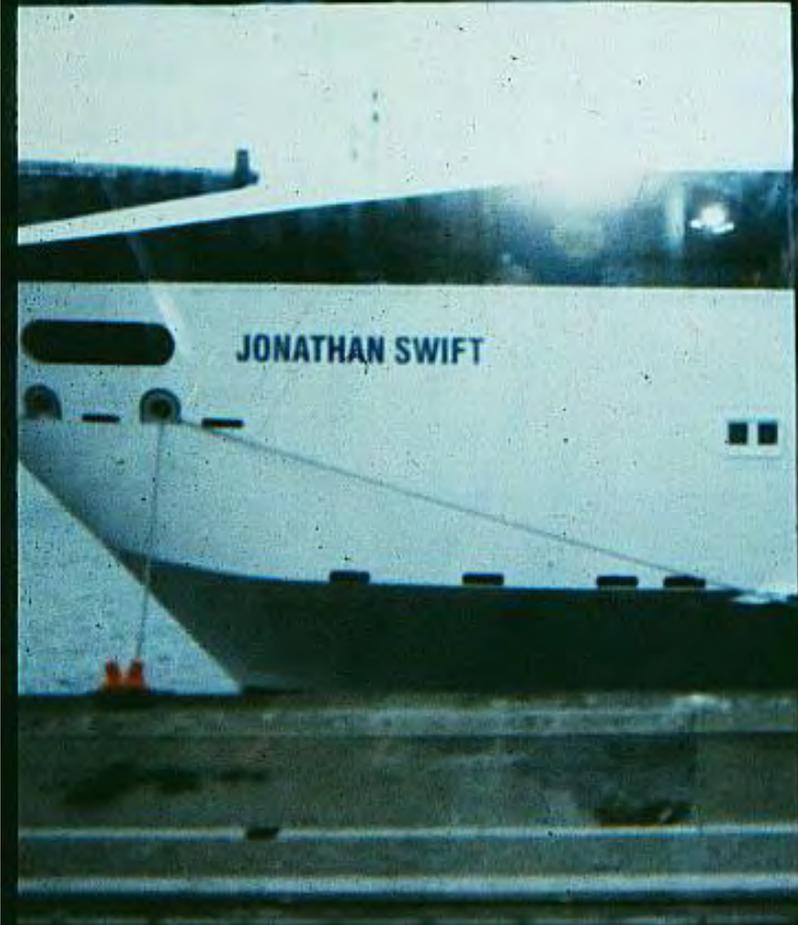


# St. Patrick's Hospital for the Mentally Infirm (12,000 Pounds)

- \* “Not fear but care” (Bethlehem/Bedlam)
- \* No violence or cooling
- \* In “the vicinity of general medical care” (St. Steven’s)
- \* Residents from Dublin region so family members could visit weekly and pray with loved ones
- \* In 1742, after writing his will, Swift himself succumbed to dementia that he feared







*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