

**Suggested Talking Points for Stephen G. Post, author of
*Dignity for Deeply Forgetful People: How Caregivers Can Meet
the Challenges of Alzheimer's Disease***

Stephen G. Post, Ph.D., is internationally recognized for his work with Alzheimer's patients, their families and allied organizations. His seminal book, *The Moral Challenge of Alzheimer's Disease: Ethical Issues from Diagnosis to Dying* (Johns Hopkins University Press) was designated a "medical classic of the century" by the *British Medical Journal*. During the 1990's his research on the dynamics of compassionate love in the lives of persons with dementia and their caregivers resulted in his being elected member of the Medical and Scientific Advisory Board of Alzheimer's Disease International. He is also one of only three recipients of the Alzheimer's Association distinguished service award "in recognition of personal and professional outreach to the Alzheimer's Association Chapters on ethics issues important to people with Alzheimer's and their families." Post began his work with the "deeply forgetful" while in Cleveland when he was as a professor of Religion and Ethics at Case Western Reserve University School of Medicine (1988-2008). He has published more than 120 articles on ethics and the care of deeply forgetful people, been quoted in more than 4000 international newspapers and magazines, including *The New York Times*, *Parade Magazine*, *The Oprah Magazine*, and many TV programs including *The Daily Show*. Post is also the author of several books including the bestselling *Why Good Things Happen to Good People* and *God and Love on Route 80: The Hidden Mystery of Human Connectedness*, which posits that One Mind connects us all. His latest, *Dignity for Deeply Forgetful People: How Caregivers Can Meet the Challenges of Alzheimer's Disease*, offers insights on the world and dignity of people with Alzheimer's and related disorders.

A graduate of the Divinity School of the University of Chicago, with training in clinical pastoral care, Post is renowned for his work on the unselfish compassionate love at the interface of science, ethics, spiritual thought, and behavioral medicine. He is the President and Director of the Institute for Research on Unlimited Love, which he co-founded with philanthropist Sir John Templeton, who personally selected Post as President in 2001. He is also founding director of the Center for Medical Humanities, Compassionate Care, and Bioethics at Stony Brook University in New York (2008 – present), where he also serves as Professor of Family, Population, and Preventative Medicine and Head of the Division of Medicine in Society. The recipient of a National Endowment for the Humanities "top public speaker award, Post uses a highly engaging style to inspire audiences with the best of medical and philosophical knowledge. Dr. Post continues to travel the globe speaking about those with memory issues and sharing about the transformative benefits of kindness, volunteering, spirituality, forgiveness and purpose.

1. Why Deeply Forgetful are Always Still Here

Why did you title your new book, *Dignity for Deeply Forgetful People*? What do you mean by the term Deeply Forgetful People?

How does using the term "deeply forgetful" help free people from early despair and encourages people to "notice" an underlying enduring self?

You also view the word "dementia" as a very harmful term that invites negative metaphors. Why is language so important in dealing with people who have Alzheimer's disease or other forms of dementia?

Suggested Talking Points continued...

What is paradoxical lucidity? You coined the phrase to describe when someone who has been unable to communicate verbally will surprisingly do so, possibly to let caregivers know that they are still there. Do most caregivers observe this phenomenon?

Many health care professionals, as well as family and friends, observe their loved ones engage in full conversations just prior to their passing. This has been called "terminal lucidity." How is this different from paradoxical lucidity, and given your years of experience, how do you explain this sudden clarity?

You've written about the importance of helping patients make connections to draw them out, such as with art, poetry, music or with Alzheimer dogs, a movement you helped start around the globe. Where do the Alzheimer's Poets, The Unforgettables Chorus, creativity and deKooning's brush and Personalized Music fit in? What are some of the ways that have proven to bring patients to unexpected levels of expression?

2. Mind over Matter

Despite appearances to the contrary, you reason underneath the neurological damage of dementia, the person is still there, however opaque, and are never "gone" or a mere "shell," and that deeply forgetful people have worth like any human being does, and so we must hold them in grace.

You wrote of your Grandma Post being an enormous influence on when you were young and she was diagnosed with dementia, and that as she became more forgetful, it never once occurred to you that her life was of any less value than your own or than anyone else's.

You find many great neuroscientists and philosophers agree with you that Mind is not derived from Matter. Why do you take a nonmaterialist position on the soul based on your experience with deeply forgetful people over the years?

You studied with Nobel Prize Laureate Sir John Eccles at Chicago, who wrote, "I maintain that the human mystery is incredibly demeaned by scientific reductionism, with its claim in promissory materialism to account eventually for all the spiritual world in terms of patterns of neuronal activity. This belief must be classed as superstition. ... We have to recognize that we are spiritual being with souls existing in a spiritual world as well as material beings with bodies and brains existing in a material world." Tell us about this quote and why you like it.

What about "symbolic rationality" (who we are) and creativity being more important than "linear rationality" (what we do)? Why is symbolic communication both possible and valuable?

In *Dignity for Deeply Forgetful People*, you write that deeply forgetful people have a consciousness that is of no lesser significance than the consciousness of all us 'hypercognitive' people who tend to disrespect them because we have more lucidity of mind. What are hypercognitive values and how do they prevent us from noticing continuing self-identity, and how have they undermined dignity?

Suggested Talking Points continued...

We are *all* a little forgetful, some of us are a lot more forgetful than we let on, and yet ‘the demented’ are mocked. What is normal forgetfulness, and when should we become concerned about our lapses in memory?

Do you believe that even if the brain deteriorates from Alzheimer’s or some other cause, like with your grandmother, we have an eternal spiritual essence within, that can still come through depending on the day. What do you think about the idea of an eternal soul?

You have said "That there is a mystery to the human mind that’s not explained by the mere material brain with its cells and tissue." And that you think that the mind, at least in some ways transcends matter, that there’s a kind of Over-Soul or infinite Mind in which we all participate in some sort of great connectivity." Please expand on this.

In your experience and research, what roll does the brain play? Do you have a theory on where our memories live?

You share that deeply forgetful people are so much more than society perceives them to be. How can society change?

3. Medical Ethics —Helping the Deeply Forgetful Preserve Their Dignity

You suggest that once a person has been diagnosed with Alzheimer's or another neurological illness, it is ideal to create a living will or a durable power of attorney for health care, so their remaining ability to make choices will be respected once they are unable to make decisions for their care.

Once a love one has declined significantly, do caregivers need to continue on with treatments for diabetes, heart disease, dialysis, and cancer? How can patients avoid technology and tubes so they can die naturally? What about artificial nutrition and hydration? Is it ever a good idea compared with assisted oral feeding? What is the secret to avoiding the intensive care unit and hospitalization in favor of hospice?

What was T-4, and why were deeply forgetful people in Germany eliminated in hypothermia experiments?

Why in American do we make caregivers spend down into near poverty? We provide social-economic “leftovers.” You suggest a nationally supported caregiver respite program. What is your model for this approach?

4. Pre-emptive Assisted Suicide

What about Pre-emptive Physician Assisted Suicide, a term you created. Please share some examples that you witnessed of PPAS? Do you consider PPS a good or a bad option, and why?

Please share the story about the San Francisco street clown who lived alone and went off to Dignitas in Switzerland?

5. Can Alzheimer’s be prevented?

There is a lot of talk about preventing Alzheimer’s by healthy aging, including diet, walking, meditation, and more. What do you think of all this?

Suggested Talking Points continued...

With all the research, why don't we have some magic bullet drug for Alzheimer's? Why had it been so difficult? Do you advise patients participate in research?

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