

Overview of Stephen G. Post's Dignity for Deeply Forgetful People



In *Dignity for Deeply Forgetful People: How Caregivers Can Meet the Challenges of Alzheimer's Disease* (John Hopkins University Press; May 31, 2022), **Stephen G. Post PhD**, recipient of the Alzheimer's Association Distinguished Service Award, shifts the focus from finding a cure for Alzheimer's to seeing and connecting with the whole person—their core personality, preferences, emotions, creativity, and capacity for joy—despite the limitations of dementia. An advocate for “deeply forgetful people” since the early 1990s, Post teaches caregivers and professionals how to connect with the self-identity that always remains, and how to communicate effectively. “*We* are not really very different from *them*,” Post drives home, “unless we choose to overvalue linear reason and independence and devalue their many other human assets.”

How do we approach a “deeply forgetful” person so as to notice and affirm their self-identity, dignity, and worth? Post has worked around the world showing caregivers how to become more aware of surprising expressions of selfhood. He offers a hopeful perspective on people with dementia that counters the negative influence of “hypercognitive” values with their unacceptable emphasis on human worth as a matter of linear rationality and strength of memory. This destructive rationalist bias, he posits, is responsible for the historical and contemporary maltreatment of this population, including the injustice of supporting them and their caregivers with mere “leftovers.”

Drawing on powerful vignettes and narratives, Post urges a deeper appreciation for the emotional presence, creativity, interdependence, musical capacities, and continuing selfhood of these “differently abled” human beings. If we allow it, they can bring out the best qualities of compassionate care in us all.

While caring for a loved one is always hard and sometimes debilitating, Post advocates for a nationally paid caregiver respite. He also shares strategies to help caregivers communicate optimally with loved ones as their disease advances. He provides practical answers to the many serious ethical questions raised by caregivers based on his several hundred community dialogues with caregivers and professionals across the US and around the world. What's more, he offers hope to everyone caring for a loved one with Alzheimer's disease—regardless of race, culture, or socioeconomic factors—and shows where they can find it.

With a powerful endorsement from His Holiness the Dalai Lama, the book title says it all: *Dignity for Deeply Forgetful People*. Post views the word “dementia” as a negative term, one exclusively of decline from a former mental state that invites oft-heard negative metaphors such as “gone, husk, shell, absent.” He uses the term “deeply forgetful people” as the language of inclusion that places us all on a continuum. Post emphasizes hope as being open to surprising expressions of self-identity and “paradoxical lucidity” – moments of remarkable clarity that are stimulated by music, art, nature, smell, and even a dementia dog — now a worldwide trained-dog movement that Dr. Post helped create. Post rejects what he terms “the hypercognitive” biases of western ethics, where the moral concern of a human being rests upon their having linear rationality (the rationality of what we do) (3rd mention of linear rationality. Rather he advocates that what matters ethically is symbolic rationality (the rationality of who we are), and consciousness itself. Thus, deeply forgetful people will identify with a symbolic object all the way to the very end stages, knowing that their identity is wrapped up in a doll they loved or a cowboy hat they wore or rosary beads they prayed.

Deeply insightful and compassionate, *Dignity for Deeply Forgetful People* is also immediately actionable. Among topics covered, Post discusses:

- How to develop the practice of noticing and responding to the inner person that endures underneath the chaos of Alzheimer's, and find hope in being "open to surprises."
- The wonder of connecting with deeply forgetful people through art, poetry, and music, which can be as simple as listening to one of their favorite songs together.
- The importance of maintaining a healthy diet and regular exercise, preferably in nature, for those living with Alzheimer's, and the value of a trained dementia support dog.
- How to help an Alzheimer's patient understand their diagnosis, with sensitivity and clarity, and why tender loving care can make a real difference in disease progression.
- How to ensure that a loved one with Alzheimer's is allowed to die with dignity and in peace, and why Post urges caution when a still lucid person is considering "preemptive physician-assisted suicide," while still providing a balanced consideration of what he calls "the big ethical question."

The afterword to the book is a highly regarded caregiver workshop on love and practical caregiving by Rev. Dr. Jade Angelica, designed to enhance the quality of life for deeply forgetful people, reduce stress and increase confidence for caregivers, and inspire a hopeful attitude for all.

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Stephen G. Post, Ph.D., is internationally renowned for his work with Alzheimer patients—a disease which effects 4.5-5 million people in the US. He is the most widely quoted thinker about dignity and love for deeply forgetful people in the world, and has addressed national conferences on all continents. His book *The Moral Challenge of Alzheimer's Disease: Ethical Issues from Diagnosis to Dying* (Johns Hopkins University Press 1995 & 2000) was designated a "medical classic of the century" by the *British Medical Journal* (2009), which wrote, "Until this pioneering work was published in 1995 the ethical aspects of the one of the most important illnesses of our aging populations were a neglected topic."

Post began his work with the "deeply forgetful" in Cleveland when he was as a professor of Religion and Ethics at Case Western Reserve University School of Medicine (1988-2008). 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 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 the author of the bestselling *Why Good Things Happen to Good People* and *God and Love on Route 80: The Hidden Mystery of Human Connectedness*.

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 Sir John Templeton in 2001. He is founder and director of the Center for Medical Humanities, Compassionate Care, and Bioethics at Stony Brook University in New York (2008 – present). 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 travels widely, speaking about those with memory issues, sharing about the transformative benefits of kindness, volunteering, spirituality, forgiveness and purpose.

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