

## Book Review

---

# Dignity for All: How the Challenges of Alzheimer's Disease Need Rethinking and Revaluing

Pre-press 15 November 2022

*Dignity for Deeply Forgetful People: How Caregivers Can Meet the Challenges of Alzheimer's Disease* by Stephen G. Post, Johns Hopkins Press, 2022, 288 pp.

One of us (Peter) should probably not be reviewing Dr. Stephen Post's new book. I am perhaps too close to its author—both a collaborator and personal friend who, in the past, encouraged me to write my own books, which I have since done with Danny, the co-author of this review. I am acknowledged in the introduction of Dr. Post's book and contributed to some of his thinking over a few decades. So why did I take on this honor and challenge to review his latest book project? I ultimately chose to co-review the book not only to recognize Post's major contributions but also to ask hopefully deeper questions about work, advocacy, and play with people with dementia and their families.

For decades, Stephen Post has been a prolific writer and traveler who has earned many accolades shared throughout the book for his consistent, often repeated, message that people with dementia, who he calls “the deeply forgetful”, are human beings deserving of dignity and that their caregivers are deserving of support. These moral precepts, which Post, currently Professor of Family, Population and Preventive Medicine & Founding Director of the Center for Medical Humanities, Compassionate Care and Bioethics, has helped instantiate in the field throughout his career, are essential. In this work, he enriches his definition of dignity with the language drawn from contemporary critical theory, arguing for us to view people

with dementia as “differently abled”, and challenging the assumptions of a hypercognitive society by grounding dignity as an inter-relational property that is intrinsic, embodied, emotional, creative, interdependent, and ludic. He does assure his reader there are new stories in this book, although he told me many come from his formative time in Cleveland at Case Western Reserve University where we were colleagues. Post recognizes the origins of some of his messages in many people, particularly our mutual colleague, the late leader in dementia care, Dr. Tom Kitwood.

In his scholarship, including that on altruism, Post aligns himself with scientific evidence and frequently bolsters his arguments calling on this form of knowledge creation. Yet at times he is also suspicious of the dominance of science. One wonders how he feels about balancing the often-countervailing efforts to find the cure and improve care/prevention? The frequently promulgated message from the powerful Alzheimer's Association (AA) is “Care today, cure tomorrow”, as if we may not need care or preventive measures tomorrow. On p.32, Post writes in a cadence consistent with AA messaging that: “We do need a magic bullet to end Alzheimer's disease, and science is doing their best to develop one with every generation of young researchers.” But on p.81 he writes, somewhat contrastingly: “By focusing on the ‘war against Alzheimer's disease’, this medicalization of Alzheimer's has also proven harmful . . .” and “clearly one important key to fulfilling the moral challenges of Alzheimer's is overcoming the strictly biomedical model.”

Does Post take on this challenge as we have in our books *The Myth of Alzheimer's* [2] and *American Dementia* [3]? In personal conversations I've had with him, he has expressed that he does not want to offend powerful advocacy groups like the AA whose work he celebrates as they in turn celebrate him. It is a fair and valid question to ask how we balance various approaches as we advocate for change in the field. How do we speak truth to power in the field that is too often self-serving and fame and fortune-seeking.

Our own view is to laud the on-the-ground care helpers in the AA while critiquing those in the C-suites whose decision-making does not always seem to be in their constituents' short and especially long-term best interests. The national AA's senior leadership has cozy relationships with the Food and Drug Administration and Biogen and pushed aggressively for the regulatory agency's disastrous Accelerated Approval of the monoclonal antibody aducanumab in 2021. [1] They claimed that the patients and their families who they purport to represent wanted anything (even a drug that only promised clinical benefit) at any cost. In the process, lack of efficacy, safety issues, economics and other essential matters were ignored as the major supporters of medicalization pushed their agenda to demonstrate that rapid progress was being made towards a "silver bullet". Fortunately, other regulatory bodies around the world as well as our government payers (Centers for Medicare/Medicaid Services) and most of the scientific community resisted their misguided efforts. What does it say about the dignity of the people with dementia, many of whom were coopted by the Association and Biogen to be outspoken advocates in its push for approval, that they would behave so selfishly and support such a travesty? This saga will likely continue with another anti-amyloid agent lecanemab where some evidence suggests that the biologic has some arguably minimal positive effects but are of such a magnitude that might not even be noticeable to family members (above the placebo effect). What are the opportunity costs of spending perhaps billions of dollars on drugs rather than public health and improving care? Fixation on the "silver bullet" too often precludes commonsense actions we could be taking societally to improve brain health, prevention, and support for persons living with dementia and their carers.

Post rightfully argues that caregivers need more practical support. Dr. Ai-jen Poos' book *The Age of Dignity: Preparing for the Elder Boom in a Changing*

*America* [4] calls for a Care Grid to enhance the provision of care, particularly at home. A creative network of caring relationships based on dignity for all is at the heart of her proposal. Unfortunately, since taking over the chapters of the AA last decade, national has limited innovation locally as they seek uniformity of messaging about finding the cure, which represents their strongest rhetorical strategy for fundraising. Fortunately, some of the largest chapters have resisted this national takeover and remain important innovators in care. The point here is not to focus on the dignity of specific groups of people but to enhance dignity for all of us as we are all in caring relationships, Although, as Post points out, we must not forget that the dignity of some groups is more vulnerable than others. Interestingly, a comprehensive report from the US government in partnership with many public and private groups argues for improving care across the lifespan, yet unfortunately mentions dignity only once [5]. Importantly, we must not forget the dignity of children with developmental disabilities and those who are subjected to the cognitive risks of severe impoverishment as we focus on older people with dementia—indeed, this is the other side of the coin of the ageism that Post interrogates, and the larger prism through which we might view and operationalize the ethics of dignity.

And can we look at caring with a new perspective that embraces all of us as caring people? Why do we potentially rob the opportunity for those living with dementia to actively "care" themselves? Such people who were caring partners before the diagnostic moment risk being relegated to being passive recipients of care rather than also offering love, kindness, and support through their own preserved personhood. For this reason, we prefer the term "care partners" or "carers" to "caregiver". The gift of dignity based on reciprocal caring belongs to everyone in the Care Grid.

What about those with less severe cognitive problems than the deeply forgetful? The AA promotes the use of controversial terms like Subjective Cognitive Decline and Mild Cognitive Impairment. Are the rules for dignity different for those who are not deeply forgetful, some of whom will never become so? What is the ontological status of their dignity? Where do the superficially forgetful fit in caring?

And perhaps last to go, or never to go in the progressive neurodegenerative process, is the immortal soul that Post alludes to many times. He and I have in the past written together about the importance of spiritual care. But the nature of the soul is interpreted in

different ways in different traditions, and Post points to Hindu, Buddhist, and other sources. Some indigenous cultures believe that elders, particularly those with cognitive challenges, are beginning the spiritual journey to an afterlife of becoming revered ancestors. Such views are a neglected, rich source for pondering the relationships between dementia and death. Post's own background as a pastoral counsellor is deeply informed by the Christian tradition, although it is not much overtly revealed in this book. One wonders: does this background inform his views about an ethical quandary such as physician assisted suicide that he will neither condone nor support? Is dignity a key part of this personal decision?

We end by celebrating the concept of dignity, which Post has dedicated his career to defending. As we agree with Post, principal-based bioethics is limiting. It focuses on characteristics of individuals like autonomy and beneficence, while too often ignoring collective justice issues, like the climate crisis, income/wealth inequality, national lead poisoning via municipal water, or the Deaths of Despair crisis (i.e., a precipitous rise in suicide, drug overdose, and alcohol-related mortality that is contributing to an overall lowering of life expectancy in the US). Dignity, too, is a relational term that often gets inappropriately limited to the individual. However, it is something we bestow and are bestowed by others, and also an emergent property resulting from state institutions and structures that create the material conditions for healthy, fair, and just societies. We are in full agreement with Post's message of solidarity with those living with dementia. In this time of crisis, where our species is facing potential extinction on a rapidly warming planet, we might gain some wisdom and essential humility that we are all cognitively challenged to remember, plan, and conduct our collective activities of daily living in ways respectful of the generations that may come. We need to think not only of the dignity of individuals and societies in existence today but also the individuals and societies yet born. Should we also consider more strongly the moral valence and even dignity of other living creatures?

As has been the practice of indigenous peoples for many millennia, seven- generations thinking embedded in nature, rooted in the past and looking to the future seems key to dignifying the world writ large in a way that builds on Post's eloquent advocacy for the deeply forgetful.

Peter J. Whitehouse, MD, PhD  
Professor  
Case Western Reserve University  
E-mail: pjlw3@case.edu

Daniel R. George, PhD, MSc  
Associate Professor  
Penn State College of Medicine  
E-mail: dgeorge1@pennstatehealth.psu.edu

## REFERENCES

- [1] Whitehouse P, Gandy S, Saini V, George DR, Larson EB, Alexander GC, Avorn J, Brownlee S, Camp C, Chertkow H, Fugh-Berman A, Howard R, Kesselheim A, Langa KM, Perry G, Richard E, Schneider L (2022) Making the case for accelerated withdrawal of aducanumab. *J Alzheimers Dis* **87**, 1003-1007.
- [2] Whitehouse P, George D (2008) *The Myth of Alzheimer's: What You Aren't Being Told About Today's Most Dreaded Diagnosis*. St Martin's Press, New York.
- [3] George D, Whitehouse P (2021) *American Dementia: Brain Health in an Unhealthy Society*. Johns Hopkins Press, Baltimore.
- [4] Poo A (2015) *The Age of Dignity: Preparing for the Elder Boom in a Changing America*. The New Press, New York.
- [5] U.S. Department of Health and Human Services, Administration for Community Living (2022) 2022 National Strategy to Support Family Caregivers. <https://acl.gov/CaregiverStrategy>. Accessed October 7, 2022.