

Deeply Forgetful



*The politics of remembering and forgetting is unsettling, to say the least. Together with emphasis on linear rationality, ableist contouring of normal bodyminds, and the throes of care work, we struggle to provide grace and dignity to those living with dementia. In this excerpt from their new book, *Solution 305: Dying Livingly* (Sternberg Press, 2025), Staci Bu Shea proposes that the “deeply remembering” could co-create and immerse themselves within cultural conceptions of reality buttressed around an ethos of care for our faulty memory and pliant identities.*

Dementia is a term used to describe a progressive and irreversible loss of neurons and brain functions, affecting memory, thinking, and social abilities in ways that fundamentally alter one’s everyday life. It’s technically a syndrome, a collection of symptoms with many different origins. There are dementia-causing diseases, such as Alzheimer’s, as well as frontotemporal dementia and dementia with Lewy bodies, but other factors are drawn from genetics, lifestyle, and the environment. Risks for dementia increase with age but it is possible to experience it earlier in life. *Dementia*, “without mind,” has become a stigmatized term. It denotes that sufferers are gone, empty, a shell of themselves. Such negative metaphors foreclose the opportunity to pay careful attention to how people continue their self-identity through their purposes and actions. I want to turn to compassionate care, virtue and well-being researcher Stephen G. Post’s reframing of dementia, calling it “deeply forgetful,” along with some of his ideas about the need for sufferers to be treated with grace and dignity.¹ Because our older population is continuing to grow and live longer, more and more people will become deeply forgetful. Such reframing can inspire creativity, and make us more curious, adaptable, even open to surprises.

The rising number of those experiencing dementia means that there are more specialized memory-care and support centers, facilities, services, and resources. There is more access to knowledge and skills concerning caretaking and managing life with disease, but care infrastructure is not as strong as it could be, and education and culture is still lacking. The value systems that still bob about in the flow of the river of capitalism, colonialism, and patriarchy have led to a care crisis in North America and Europe (which is also not exclusive to these countries), but they still sing to the tune of innovation and private enterprise. More pan-Confucian perspectives in

1. Stephen G. Post, *Dignity for Deeply Forgetful People: How Caregivers Can Meet the Challenges of Alzheimer’s Disease* (Baltimore: Johns Hopkins University Press, 2022).



China and Japan, and other cultures around the world, integrate deeply forgetful people into daily life, elders are still part of and taken care of by family and extended community, with these relations emphasized as being important.² Coming back to the Netherlands, the Hogeweyk dementia village is paving the way with a new vision for how to care for the specific needs of deeply forgetful people and is an inspiration for humanizing care for this growing demographic. In the US, there is increased concern (and industry) for deeply forgetful people, with more conversations taking place (motivated by the example of the Hogeweyk) about reusing vacant malls or other large buildings to establish dementia villages. Funded both by government and village residents, the Hogeweyk's mission is to deinstitutionalize care and make deeply forgetful people more part of society. New models will continue to be envisioned and designed to improve dementia care, but the interpersonal dimension needs to catch up. It is the rest of us not-yet-deeply-forgetful people who must also find ways to ensure that people experiencing dementia are integrated into society. First, because deeply forgetful people are part of our community and deserve compassion, dignity and justice; and second, because we too are already forgetful because we are human, and will eventually become deeply forgetful.

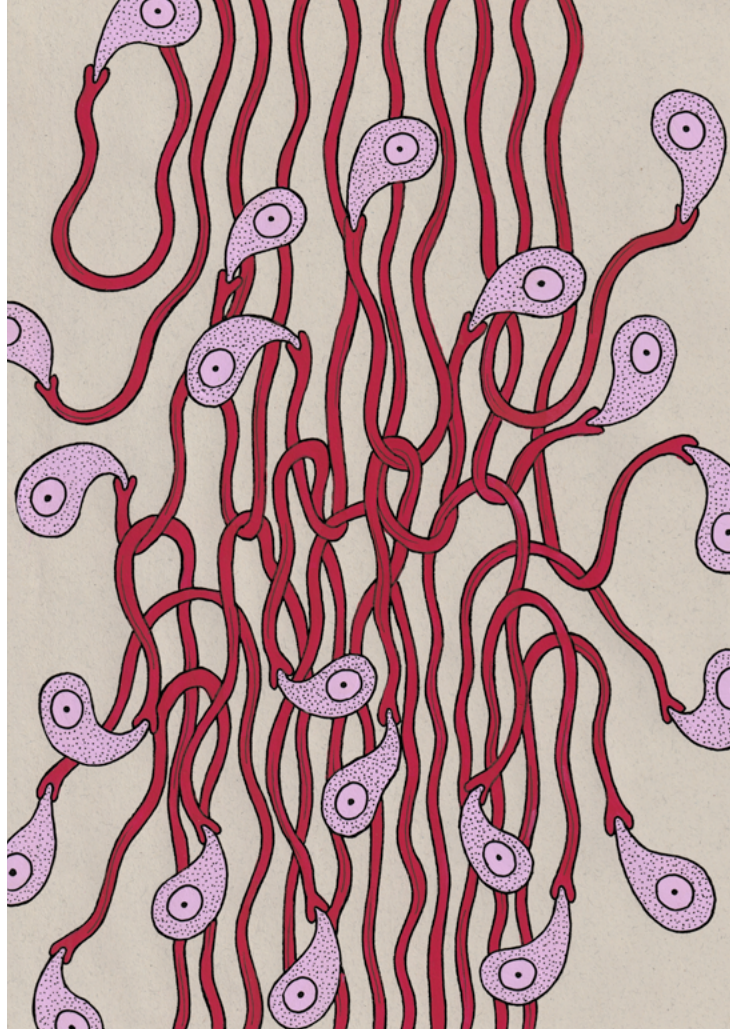
In crafting this idea, I don't want to minimize the significant challenges and hardships faced by caregivers and loved ones. While I can't imagine the unique situation which you, dear reader, have gone through, I do understand the frustration and sheer amount of grief (often ambiguous or anticipatory grief) experienced when a loved one becomes increasingly, deeply forgetful, so much so that they no longer know who you are. There is perhaps nothing more silently soul-crushing than this when love is expected through a clear scope of mutual recognition. The level of confusion or harm that can also take place shouldn't be understated either, but I think the interpersonal and institutional are always in dialogue. As dementia care specialist Teepa Snow says, dementia doesn't rob someone of their dignity, it is our reaction to them that does. It is precisely because of this complex reality that turning toward the deeply forgetful and its relationality is a useful philosophical modus for a different way of being in the world, both in knowledge and practice. It just requires vulnerability and a daily dose of letting go.

While each person's experience is distinct, in general the process of deeply forgetting begins with losing aspects of oneself. The real suffering commences when you are insightful of and frightened by these losses and fearful of more to come. You then reach a "kind point," Post describes, where you forget that you have forgotten. Having conversations about the early signs of forgetfulness or dementia diagnosis is fraught. The family is not sure whether or not to tell grandma or grandpa, who is opaque but still there, that they are becoming forgetful.

2. Hing Cheung Yiu, Yuli Zang, Jocelyn Han Shi Chew, and Janita Pak Chun Chau, "The Influence of Confucianism on the Perceptions and Process of Caring Among Family Caregivers of Persons with Dementia: A Qualitative Study," *Journal of Transcultural Nursing* 32, no. 2 (2020): 153-160.



The initially forgetful person is aware that something is going on, but tells the doctor not to tell the family. We don't have a lot of tools and resources for navigating this, often needing to learn a great deal in a short amount of time (or working together with a dementia doula). According to Post, if one is diagnosed with a disease that causes dementia early on, they can start to have meaningful encounters and begin advanced care and end-of-life planning. While it is a sensitive issue and some may not be inspired to do such a thing, an initially forgetful



person can let those around them know about the diagnosis. Neighbors and local store workers can be informed to give them the opportunity to extend support. While being capacitated there is potential to act and co-craft relational encounters. This is a great responsibility for the initially forgetful, or those with other conditions that inspire an imminent unraveling—that they should make arrangements in good time. This is especially so for those in positions of power, who tend to avoid such vulnerabilities for the sake of not losing control, which ultimately causes more damage. But for us common people, the “deeply remembering”—a term I use for the sake of making the tension between the states clearer—must create space for the deeply forgetful and include them within the community, integrating them into daily life at all levels. This way we can be more prepared. We have to start practicing losing ourselves with each other.



The deeply remembering make sense of and find their place in chronological time, but this is also the struggle. The limbic system, the part of the brain that is involved in emotion, memory, and behavior, is designed for survival, and involves looking both at the past and future to understand what challenges we might face. Most often these anticipated events are not truly dangerous or even within our control. This form of sense-making narration helps deeply remembering people to define their identity and purpose. They are often more aware of their attachments and losses, although they might not know how to navigate it. They often inhabit the present by moving between prospection and retrospection in their time machines, for better or worse. It is very difficult to conceive our future selves, much in the same way it is hard to fathom our own death. In financial and psychological terms, there is a name for the disregarding of the future in relation to the present: “temporal discounting.” According to studies led by psychology and economics researcher Hal Hershfield, we tend to perceive our future selves as other people, and therefore act in ways that are often shortsighted, prioritizing what benefits us now rather than what we might do in the present that could help us in the future. In individualistic cultures this proves to be a challenge. While we would be better off establishing a more salient, warm, and closer relationship with our future self let alone others, we also have a problem inhabiting the present.

When interacting with someone who is deeply forgetful, the deeply remembering is pushed out of chronological time. They must inhabit the pure present together. Fidelity must be recast anew. For the deeply remembering, in the face of the deeply forgetful, the capacity to cope with suffering and the capacity to find joy throughout time require different skills and training, but both are incredibly important. The better deeply remembering people are trained in these skills the more capacious and compassionate they will be in navigating the present with the deeply forgetful. Post argues that what matters more is symbolic rationality (the rationality of who we are) and consciousness itself, as opposed to linear rationality (the rationality of what we do) and the strength of memory. But the politics of remembering are contentious to begin with, and memory is mishmash. Psychologist Elizabeth Loftus has studied how memories are malleable and often unreliable, that memory can be reconstructed through inference, imagination, and suggestibility. Interpersonally, this can be very uncomfortable. Ideologically and institutionally, it can (and does) hold grave consequences ensuring a repetition of violence and subjugation in the existing matrix of power relations. Reality is like how poet Gertrude Stein described the “continuous present” in *Composition as Explanation* (1925–26), that “the only thing that is different from one time to another is what is seen and what is seen depends upon how everybody is doing everything.” Could it be that we hold so strongly to memory to have a sense



of control, to avoid vulnerability, against the truth that we are purely fragile, and that necessitates intense responsibility to each other that we're unsure how to hold let alone handle? We'll need new prompts and tools for remembering based on a value system that prioritizes dignified life and death at all costs. As both Milan Kundera and bell hooks have written, our struggle is the struggle of memory against forgetting. So, only monuments for feats of love and care, altars, and wearable symbols for alignment with inevitable, ongoing transformation. Inevitably this worlding and these forms of relating extend dignity to varying states of physical, mental, emotional, and spiritual health. The deeply remembering can further humanize the deeply forgetful through the signs and expressions of pain (something medical anthropologist Natashe Lemos Dekker has researched and written extensively about). Through acts of kindness, through music, art, and poetry, through interaction, moments of re-mentia are possible and the deeply remembering will be taken aback, in awe. It's all another rearrangement. If the deeply forgetful person is transgender and they can only remember their gender assigned at birth, then the deeply remembering can follow their lead, knowing that their gender is not fixed or static, and find ways to respectfully make it work. Through numerous strategies to slow down and rest, the deeply remembering can learn to savor the moment. Forget-me-nots bloom only because they do. It's the inhabiting of this space, the enmeshing of instabilities, the collapsing of time, that could profoundly reshape our sense of values and ethics with regards to the future of care against medical capitalism, for both the remembering and forgetful—which is to say, all of us.

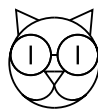
Acknowledgements

“Deeply Forgetful” is inspired by Stephen G. Post’s book *Dignity for Deeply Forgetful People: How Caregivers Can Meet the Challenges of Alzheimer’s Disease* (2022). Thanks to Simon(e) van Saarloos for our conversations about plasticity and transelders and for recommending *Queer Silence: On Disability and Rhetorical Absence* (2022) by J. Logan Smilges. See van Saarloos publication *Against Ageism: A Queer Manifesto* (2023) for their valuable thoughts on time and aging. For more information about dementia care, see *Positive Approach to Care* led by American dementia care specialist Teepa Snow.



BIO

Staci Bu Shea (b. Miami, 1988) is a curator, writer, and death doula based in Utrecht, the Netherlands. Bu Shea was curator at Casco Art Institute: Working for the Commons (Utrecht, 2017-2022) and cocurated *Barbara Hammer: Evidentiary Bodies* at Leslie-Lohman Museum of Art (New York, 2017). Bu Shea holds an MA from the Center for Curatorial Studies, Bard College (Annandale-on-Hudson, 2016).



Wild Papers editor: Ingo Niermann

Copy-editing: Blanche Craig

Illustration: Eva Fàbregas

Graphic design: Ana Domínguez Studio

© 2025, Staci Bu Shea, Eva Fàbregas & Wild Publishing,

a division of Institute Art Gender Nature at HGK Basel FHNW, Switzerland