

## ON THE DIGNITY OF DEEPLY FORGETFUL PEOPLE

**Stephen Post**

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I offer these thoughts on the dignity of “deeply forgetful people.” After three decades of listening and learning from them, I have discovered many wonderful things otherwise undiscoverable. For example, a caregiver's hope rests mostly in being “open to surprises” – that is, to sporadic expressions of continuing self-identity from their loved one despite limits in speech and degrees of withdrawal from the external world. A deeply forgetful person, then, is never a “husk” or a “shell” or simply “gone,” although those who do not get close to them will not realize this. Our opportunity as caregivers is to discover this secret: However deeply forgetful a person might become degrees of self-identity endure, underneath it all, but one must look and listen to discover it.

I also write to encourage the wider cultural and social recognition of this enduring self-identity, and to the rewards of being with deeply forgetful people that we almost never recognize because of the dominance of “hyper-cognitive values” (Post, 1995). That those who are more forgetful than most are never “gone” or “shells” or “husks,” but are always present and can teach all of us to treat the vulnerable of mind with kindness.

Can we as individuals and as a society finally discover, and acknowledge, the equal dignity of deeply forgetful people? Can we overcome the stigma society attaches to their condition by spending time with deeply forgetful people and uncovering the self-identity that continues, despite their limited abilities to communicate by speech? Can we respect them enough to work with their remaining emotional, relational, and creative capacities? Can we rethink the ethical issues that arise between diagnosis and dying, so that they can lead more peaceful lives?

We live in a Western culture dominated by elevated expectations of rationalism and economic productivity, so clarity of mind is for many of us what makes life worthwhile. Descartes' proposition *cogito, ergo sum* -- “I think, therefore I am” -- can rightly be replaced with “I will, feel, and relate while only somewhat disconnected from my former self, and therefore, I am.” This, anyway, is my purpose in writing. Human beings are much more than just keen minds, or recording devices that can therefore create economic value. One of my colleagues, an epidemiologist who studies AIDS, tells the story of a young man with AIDS-related dementia who felt “written off” by his mentally agile friends. In response, he started a small business selling shirts with the motto “Sum, I am” to people with AIDS.

The good news is that things can be different. It is morally noteworthy that in some cultures, such as the Chinese, there is no interest in associating dementia in old age with disease. Instead, they prefer to think of it as the result of a natural progression; they accept the notion of a life cycle

that concludes with a second childhood, and are not fighting our “war” against dementia as the worst condition imaginable. In China, dementia is not so much feared as accepted. Given our scant progress in finding any drug that cures, slows, or delays Alzheimer’s, it makes sense to work harder at encouraging the acceptance of forgetfulness in the aging, and at promoting the many inspiring ways to enhance the quality of life of deeply forgetful people and their caregivers.

If we look closely we can see that deeply forgetful people have strengths; for example, they often remember how to perform tasks they did earlier in life, tasks that can give them a sense of fulfillment. A man who suffered severe dementia still remembered one of his boyhood tasks (carrying wood) and walking with a bit of kindling in his hand dramatically improved his self-esteem and emotional state. Behaviors that appear meaningless may not be so: the person who wanders may actually be searching for something or someone, and we can respond by accepting their questing. Environments can be designed to provide visual, tactile, auditory, and physical stimulation without causing sensory overload and consequent distress, and cues can be built in to help residents find their way around without feeling lost, protecting them while maximizing their ambulatory opportunities and