

In Response to Margaret M. Gullette

Stephen G. Post

I appreciate Margaret M. Gullette's perspective. Let me try to amplify an alternative for the caregiver who might otherwise consider turning to a secretive euthanasia. In general terms, euthanasia is distinguished from treatment refusal, treatment withdrawal, and assisted suicide. In the contemporary medical literature, it is reserved for the actual killing of one person by another through some impingement, be it a lethal injection or a pillow over the face. This goes beyond prescribing lethal pills and allowing the patient in active agency to swallow them (assisted suicide). Treatment refusal and withdrawal are so common clinically as to be largely noncontroversial in most cases, and while assisted suicide is illegal in most states in the U.S., it is legal in a few and certainly legal in some nations around the world. Euthanasia is generally illegal even where assisted suicide is legal.

In an aging society, we must acknowledge the temptation to senicide. The practice (i.e., the killing of the senile elderly, usually by adult children) has both a long history and modern defenders. Like Raskolnikov in *Crime and Punishment*, we might set aside any senicidal hesitations and boldly proclaim, "Anyway, to hell with it!" After all, these persons with dementia or stroke are already biographically dead, and they have more or less outlived their brains. And it might be said that biological death is not at all terrible when compared to the death of the mind before the death of the body, by stroke or by protein beta plaques.

Some anthropologists report that senicide has an "interesting" and even honored history in societies where elderly persons are allowed to live only so long as their faculties are retained. Otherwise, they might be marooned on an ice floe or, as was once practiced in rural Japan, left to die on top of mountains, abandoned and disoriented (Barash 18). And why not, for they are already "gone," "shells," and "mere husks," as the metaphors are sometimes applied, even by family members and philosophers (Howell 657). Some philosophers

even make the regrettable and false argument that the deeply forgetful are “nonpersons,” in contrast to “persons” who can envision rational plans and operationalize them.

I would hope that we never succumb to such dehumanizing and narrow perspectives. Such perspectives will never entirely disappear, but we need not be swayed by them. In his last period of sanity, Nietzsche really did take the view that: “The invalid is a parasite on society. In a certain state it is indecent to go on living” (88). Is not the person with dementia the perfect parasite, a grotesque affront to the values of cognitive enhancement and economic productivity? Why should we tolerate the rise of the weak? Regrettably, such perspectives can be attractive under distorted circumstances of eugenics and racism. From offices in Berlin at Tiergartenstrasse 4, the “T-4 Project” began in 1939 and concluded in 1941. Under the direction of Wurzburg Professor of Psychiatry Werner Hyde, an estimated 94,000 psychiatric patients, many of them with dementia, were killed in hypothermia vats of ice in the cold night air (Muller-Hill).

There is wisdom in the Decalogue when it places the commandment, “Honor thy father and thy mother” first among the social precepts. This is the first commandment that deals exclusively with human relations, rather than divine-human ones. Presumably, parental love for children is strongly supported by innate reproductive drives, and is therefore more or less a given that needs no “Thou shalt” to support it—although child abuse is rampant, and parental love seems hardwired only until the child gets really annoying. A child, anyway, is cute and on an intriguing upward developmental curve to which the parent enjoys contributing. But the aging parent who has dementia is not cute, and may be wasting precious resources that could be directed at future generations.

No doubt, it was easier to abide by the filial commandment 200 years ago, when mother or father would rarely live long enough to experience the chronic frailties of old age, although some did live into their seventies and eighties, or perhaps beyond, very occasionally. The demographic transition to an aging

society *has put more pressure on this commandment than any other*. Under such circumstances, it is somewhat tempting to dismiss elderly persons with dementia as “nonpersons” unworthy of life.

The utilitarian pursuit of “the greatest good of the greatest number” seems to easily set aside duties to the neediest, and even to maintaining their lives, if this promotes the so-called “happiness” of some majority, however specified. Utilitarianism is, of course, ambivalent about any prohibition on human actions, such as killing. Coupled with hypercognitive theories of personhood that exclude the cognitively disabled, there is no reason to be sanguine about the implications for the deeply forgetful.

Princeton University’s Peter Singer, a utilitarian philosopher, argues that “intellectually disabled humans” do not have a right to life in any full sense and seems to offer no compelling reasons for not killing them if they lack rationality and, certainly, self-consciousness (101). I am uncertain what Singer would say to an audience of family caregivers for persons with dementia. He is clear that killing a baby (painlessly, of course) is preferable to killing a “person,” although I think that most parents who sacrifice time and energy in enormous volume to be sure that their newborns have a good developmental start in life would find Singer’s abstractions strange. My interpretation of his writings is that the nonvoluntary euthanasia (killing) of those who, through “old age have permanently lost the capacity to understand the issue involved,” would be more or less acceptable (179). Of course he thinks this, given his narrow view on “personhood” that removed whole classes of individuals from the protective umbrella of “do no harm.” Singer’s “indicators of personhood” are “self-awareness, self-control, a sense of the future, a sense of the past, the capacity to relate to others, concern for others, communication, and curiosity” (86). This strikes me as exceedingly narrow.

Had Singer much experience with the deeply forgetful, he would know that caregivers are regularly surprised by continuing self identity in their loved ones. Moreover, the self has many layers that Singer ignores: *creative, symbolic, emotional, relational, somatic, musical, rhythmic, aesthetic, olfactory (smell), spiritual, tactile, and cognitive*. Selfhood exists at all these levels, and can often be prompted.

My concern with the severity of hypercognitive theories of personhood is resonant with the views of Mahatma Gandhi, who defined religion as “the service of the helpless,” and commented that “rationalists are admirable beings, rationalism is a hideous monster when it claims for itself omnipotence” (*Essential* 229; 214). He contrasted his Hindu ethics of “*ahimsa*” (nonharm) with both “the greatest good of the greatest number” (the principle of utilitarianism) and “might is right” (*Law* 53). Instead, he offers this: “With God, it is the good of all that counts” (53).

As Jenny Teichman argues regarding “personhood” theories, the restricted definition of person “has the consequence that some people are not persons and is therefore rather similar to the doctrine that only white Anglo-Saxon Protestants really matter” (181). Better to quicken the spirit of beneficence toward the weakened than to undermine it. Historically, this quickening is related to a shift in the moral tone of western civilization that even gives preference to the vulnerable and weak, and that makes beneficent service the highest virtue.

I fully expect my philosophical critics to respond to the above comments by dismissing them. Some may assert that even if a human being slips below the “objective” category of person, he or she may still retain some socially attributed persona, or still be valued as a nonperson in certain respects. But I view this dualism between “person” and “nonperson” as discriminatory and divisive. The fitting response to the increasing incidence of deep forgetfulness in our aging society is the enlargement of our sense of human worth to counter an exclusionary emphasis on rationality, efficient use of time and energy, ability to control distracting impulses, thrift, economic success, self-reliance, “language advantage,” and the like.

Indeed, we might concentrate on the hints at continuing self identity deep into progressive dementia, and celebrate these rather than draw on negative metaphors like “empty,” “gone,” “absent,” “shell,” and the like. More and more, we are discovering that even the most deeply forgetful, when prompted by personalized music, will regain some degree of self-awareness and self-

identity (see www.musicandmemory.org). In fact, the deeply forgetful are able to exercise many capacities.

In the lives of caregivers for the deeply forgetful, hope might be best defined as “an openness to surprises.” This is a definition that is not intended to trivialize the profound anguish felt by carers, or by the deeply forgetful themselves until they reach that point where they forget that they forget. Dementia, in its intractable, progressive, and irreversible form, is often caused by Alzheimer’s disease (about 60 percent of cases). There is much bleakness in the insidious peeling away of memories and capacities. It is known as the “autobiographical disease” and we read of “protracted grief.” Where is hope? Is there any at all?

The idea of hope as “being open to surprises” at the various levels of continuing self-identity listed above is not something this author simply dreamed up. It emerges from twenty years of working with carers in support groups and community dialogues. Yes, there is an assault on the story of a life, but despite the losses, there are also sporadic indicators of continuing self-identity that make caring meaningful.

Perhaps we ought not to even speak of individuals as *demented*, because the term is so often used in a derogatory manner and lends itself to dehumanization and despair. The *deeply forgetful* suggests continuity with a shared humanity, for which forgetfulness is a problem of degree, from the absent-minded professor to the shopper who has forgotten where the car is parked, from the patient who has just awakened after shock therapy to the athlete who has suffered one too many concussions, from the young child whose capacities for memory have not yet developed to the adolescent with attention deficit disorder.

I would challenge some of our filmmakers and scriptwriters to try and capture the many levels of continuing self-identity and to remind society of them. It is the moment of expressed self-identity that allows caregivers to feel gratification and meaning in astonishing works of love.

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Reply by Margaret M. Gullette (January 6, 2014 at 7:23 pm)

Warm thanks to Stephen G. Post for his thoughtful statement. It is a sad comment on our age culture that he and I (and others) feel it necessary to argue so hard for something enshrined in the Fifth Commandment.

I offer two brief additions. I have recently seen a fiction film that depicts the (alleged) Japanese rural "custom" of killing people at the age of 70. The *Ballad of Nurayama* (1958) demonstrates how religion might inculcate in the morituri—even, as in this case, a loving, healthy, and highly productive woman who is the matriarch of her family—the active desire to be carried up a mountain by her reluctant son and left to die. Japanese in 1958 knew real scarcity first-hand, while in our time the economy of scarcity is created by the 1%, while the discourse that attaches the blame to old people (rather than say, the NSA) is politically motivated.

On a happier note: Since I wrote "Euthanasia as a Caregiving Fantasy" in 2013, a Canadian film appeared that answers our call for artists to address the humanity of those who are becoming "deeply forgetful" and to admire the care-givers who are deeply loving. The film, written and directed by Michael McGowan, is called "Still Mine." My essay-review about it, "Passion is Contagious," appears on two blogs on Silver Century.

http://www.silvercentury.org/polBlogs.cfm?doctype_code=Blog&doc_id=82

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