

**Dementia and the Human Good: Caring, Meaning, and Remembering**  
Bruce Jennings

*Twenty-First Annual Symposium in Tribute to Rudolf Wittkower*  
The Monuments Conservancy  
New York, NY  
March 18, 2011

I

“Dementia and the human good” is a phrase that gets our attention. Can this be serious? Surely dementia is the antithesis, the erasure, of the human good. Dreadful though this cruel, unrelenting disease is, I believe that only dementia without care, or with manifestly inadequate caregiving in a frightened, indifferent society, is truly the antithesis of the human good. Caring properly understood is closely aligned with the notion of love as *agape*. Caring aims for the good of the other for its own sake and recognizes the other as a being of intrinsic value. Dementia care, no less than any other situation of caring and care giving, seeks the good of the individual cared for. That is the difference between the caring and the custodial.

My concern is that in the realm of dementia care we often lose sight of that distinction; we narrow the boundaries of our conception of the goals of care so tightly that we end with essentially custodial goals of comfort and safety. We do this because we reduce the demented individual from the status of a subject to the status of an object, “a body wholly body, fluttering/ Its empty sleeves,” as Wallace Stevens put it, perhaps thinking of a parallel image from Yeats (“An aged man is but a paltry thing/A tattered coat upon a stick...”).<sup>1</sup> I seek to understand how a demented individual can still be a subject of care and love. I seek to understand how a demented individual can still be understood as a agent and as a person of moral significance and standing. My suggestion

is that the human good sought in dementia care is the preservation and nurturing of a remaining capacity for agency and personhood; facilitating a form of agency that involves the relational activity of making meaning and facilitating a form of personhood that derives from a memory of a past life more than from the anticipation of a future one. I call these “semantic agency” and “memorial personhood.” From an ethical point of view, dementia caring should aim for the human good in this sense because it is a matter of right relationship and right recognition.<sup>2</sup>

Being allowed to make meaning in the world by entering into relationships with others and being seen as a subject or person in the context of a past as well as a present and a future are of course very general features of any life of human flourishing and moral recognition. In the face of dementia, these general principles require special interpretation and special provision. For example, moral personhood becomes very important for those without a future and for those who cannot sustain continuity of self over time. Persons living with dementia require special help in sustaining their moral status and identity. Yes, but then, who among us, we temporally able-minded, does not need such help? Who can really sustain themselves, as selves, completely alone?

My reflections touch upon two primary quandaries above all. First, I am interested in the conceptual framing and function of our public and private—policy, clinical, and familial—discourse concerning dementia. Second, I am interested in the substantive philosophical and conceptual content of that discourse. I perceive dementia itself as a hermeneutic problem and dementia care as a hermeneutic process, a form of interpretive practice. I want to bring to the foreground key concepts of meaning, agency, the subject of care, and the ethics of recognition and memory, using these concepts to displace the

prevailing discourse of meaninglessness, passivity, objectification, and loss. All too often, we focus on the diminished thing, when we should seek instead a re-placed plenitude.<sup>3</sup>

## II

Dementia care is a form of reminding. It is reminding in the ordinary sense of recalling to mind something that has been forgotten; in dementia care a person's long-term memory of past abilities and experiences can be nurtured and used therapeutically, and the loss of short-term memory and behavioral control can (to some extent) be mitigated and compensated for. But it is also "re-minding" in the more radical sense of reconstructing the subject, the person.

Dementia care involves the ordeal of reminding—the rediscovering and refashioning of personal and social mind. Or (should we say?) it is the process in and through which the individual who receives care, those who provide care, and the environment within which caring takes place each take part in doing this refashioning of mind. Reminding is changing the environment and the external support system that surrounds the person so that *different* abilities do not become *the absence of* abilities. Reminding, as the play on words suggests, is re-mem-bering who one is, most fundamentally, as a relational human subject, person, agent—a maker and a interpreter of meaning—in the midst of meaning interpreting and meaning responding others. I am using this particular terminology deliberately and with some care. I do not believe that these concepts are out of place or inappropriate in application to individuals with dementia (across most of its spectrum). The tragedy of dementia is not so much that it alters brain function and changes what people can think and do; the real tragedy occurs when and if we allow those changes to objectify persons, reducing them to their impaired

body and altered behavior, rather working with them to re-mind themselves and to be re-membered among us.<sup>4</sup>

Why is it hard to believe this? One of the most powerful assumptions in our habitual way of thinking and feeling about dementia is that the erosion and loss of brain function precludes relationality in a deep sense and hence precludes being a social persona and having a social identity. Closely allied with this is the assumption that the impairment of brain must of necessity erase the ability to make meaning and erode one's membership in the human moral community. We need to reexamine several aspects of the symbolic and emotional economy of our response to brain injury and self-transformation. These are the paradigms, icons, and idioms, inherited from our tradition, with which we most habitually perceive, imagine, think, and feel. They inform our assumptions, attitudes, and reactions to dementia. They are the stuff of its imagined reality. They are our first line of defense when dementia arrives, a most unwelcome visitor, and enters our families.

I suggest that these ready-made patterns of perception and expectation are not reliable, nor are these patterns equal to the task presented by the unique symptoms, disabilities, and needs of an individual who has sustained dementia and now must live with and in spite of it. All too often family members (and other caregivers) discover that the conceptual and symbolic resources of their cultural tradition are not sufficient or fully serviceable. But then they have to fashion new patterns and new structures of meaning for themselves.<sup>5</sup> This is a difficult and terrifying thing to do. Depending upon the stage of the progressive dementia and the extent of loss of capacity, the person living with dementia may assimilate and take such patterns of response into his or her own work of

reminding and healing, and in the process will have to refashion expectations about dementia previously drawn from the culture as well.

### III

A dementia such as Alzheimer Disease is both a disease of the brain and a malady of the mind.<sup>6</sup> As a disease, dementia is an attack on the brain, upsetting its enormously complex and delicate chemistry and circuitry. Beyond that, dementia is a human catastrophe because it disrupts and distorts the mind, confounding and eventually overwhelming its remarkable durability and resiliency. It is primarily in the former domain that most of our recent, exciting knowledge in the field of dementia has come.<sup>7</sup> The human brain is finally beginning to yield its secrets. Yet new knowledge, new perspectives, and new insights are no less necessary in the realm of the mind and the self—in the realm of phenomenological understanding, interpersonal transaction, self-consciousness, memory, and judgment. New insight is also needed in the realm of reflexive self-monitoring, self-control, and the determinants of culturally and situationally appropriate behavior. When the social and transactional capacities begin to erode and to deteriorate markedly over time, a difficult threshold of personal, ethical, social, and legal questions arise.

The appropriate goals of care in dementia should be those of *rehabilitation* in the broad and etymological sense of the word—to bring the person back to the conditions of the living of a life. Rehabilitation is a form of conserving, an endeavor of sustaining. It is sustaining the integrity of the person, through a meaningful self-identity; the sustaining of effective, albeit different and non-normal capacity for communicative and relational

agency, and sustaining the individual's identity as a moral subject, as a being worthy of memory and respect and regard. Healing, wholeness, and human flourishing, even in the labyrinth of dementia, come from two sources. First, they come from the exercise of semantic agency, albeit in new ways and with new strategies and forms of assistance that outwit impairment; and second human flourishing comes from recognition: from being re-membered and seen as a self who is a subject rather than an object.

#### IV

Semantic agency refers to the capacity to communicate, to engage in meaning sending and receiving (i.e. transactional) relationships with others, and to evince understanding and evaluation of such communication. I argue on hermeneutic and clinical grounds that this capacity persists *in properly structured, supportive care-giving environments* even when high level cognitive, speech, executive, and short-term memory functioning have been impaired. Semantic agency is the capacity for engaging in the activity of making and experiencing meaning, where meaning taps a level or circuit of communication between human beings that goes beyond unilateral sensation or sensate experience.<sup>8</sup> Of course, communication here does not mean verbal or even semiotic communication, for the capacity to manipulate previously learned semiotic systems may be lost with some dementia patients. But touch, gesture, facial expression, posture, eye contact, even control of body movements in order to permit prolonged physical closeness, like sitting together, can conceivably be media of semantic agency, and these may endure even when memory, speech, functional capacities for activities of daily living (ADLs) and self-care, and other capacities are compromised.

The philosophical theory of the human good to which I am appealing can be called an agency conception of the good or a theory of human capabilities or human flourishing. It is line of theorizing that can be traced back to Aristotle, and has two contemporary voices in the work of the Nobel prize winning economist, Amartya Sen and the well-known philosopher, Martha Nussbaum. This type of philosophical theory bases an understanding of the good life on an account of those functions, capacities, and excellences that are most fully and constitutively human. To the extent that we attain and master those capacities, and to the extent that we negate those conditions that would stunt or undermine those capacities, we flourish as human beings. Theories of this type also usually have a developmental component built into them, for those most fully human capacities are ones that are not mastered at birth or automatically expressed by instinct, but must be developed and nurtured by education, interaction with others, and practice over the course of a life time. To the extent, then, that the individual continues to grow and develop throughout her life, the quality of life is enhanced thereby.<sup>9</sup>

Once again, accounts of these most fully human capacities differ among philosophers working in this tradition of theorizing, but as a generalization we can say that philosophical accounts of this type usually emphasize the human capacity to express and to experience meaning in social relationships of intimacy, friendship, and cooperation; the capacity to use reason and to develop and follow a life-plan of self-fulfillment and self-realization; the capacity for independence and self-reliance; and the human need for an appropriate social and cultural environment that provides the individual with various types of resources—material, symbolic, spiritual—necessary to live a developmentally human life and to meet both basic and secondary needs.

Making sense together, remembering a distant past and self, making judgments and expressing evaluations, even though non-verbally through emotional responses and bodily, kinetic gestures—these are some of the constituent elements or capabilities of a good life, a life of quality and value, whatever the degree of one’s other abilities at short-term memory processing and ratiocination. Those without the impairments of dementia do these, and other things, in many different ways with an audience of others or with an audience of various “selves” or perspectives within their own minds. Those with the impairments of dementia do them differently, more tenuously, and need different kinds of audiences and help, but they do them, sometimes for remarkably long into the progress of the disease.

## V

For those who provide care for those living with dementia, there is more than the work of keeping semantic agency alive; there is also a primary duty to sustain the individual’s status as a moral subject, a member of a fabric of moral relationships and community. I seek to explore this by deploying the concept of “memorial personhood.” Memorial personhood refers to the status of the demented individual within the moral life world of semantic agents and those engaged in the form of moral agency constituted by the giving of care. This particular type and status of personhood is not often recognized as such.<sup>10</sup> It does not derive from the capacities of the individual, even from the capacity for semantic agency. It derives instead from three components of the individual’s ontological situation: need, vulnerability, and the duty called forth by remembered identity. (Of course, this is a duty incumbent on others, not on the demented individual.)

To be a memorial person is to be a self in the imagination and memory of others; which, on this view, is just what it is to be a self. It is to be a self whose identity and life must be honored and acknowledged by those who can, even if it no longer can be by the person himself or herself. And to be a person of any type—including a memorial person—is to be a self to whom as Arthur Miller put it in *Death of a Salesman*, “attention must be paid.”

Memorial personhood fills the neglected place of memory in morality. It reaffirms the imperative for an ongoing recognition of individuals living with dementia as members of a human moral community, even in the face of their disability and impairment and loss of “use” or “productivity”; even in the face of the end of their “growth.” A moral community is a community of constant re-naming and re-membering.

The basic idea here is that that maintaining, sustaining, and creating relationships—connections and commitments—with the impaired subject is itself a duty of ethical responsibility for other individuals in the moral person’s environment. If I am a moral subject, I cannot rightfully be ignored, abandoned, exiled from the space of connection between selves that we call the moral community. Moreover, to relate to someone as a moral subject is different from relating to them as a moral object, as an object of moral concern, affection, empathy, kindness, even love. A moral object may be well cared for; a moral subject calls forth and commands care by dint of his or her identity, status, and agency in a shared skein of subject status, a moral commons or space of moral recognition.

One final point is crucial. The moral duties implicated by dementia and the human good are social and communal as well as personal. Caregivers as individuals, social

institutions, such as nursing homes, and public policies affecting chronic and long-term care systems and financing all have an obligation to provide the environment, resources, services, and human presence necessary to sustain and conserve semantic agency and (memorial) personhood during the course of life with dementia.

Public art and public monuments and memorials are tangible expressions of who we are as a community, our shared past, our fabric of values and ideals, and our common future. But if this is manifest in paint, metal, and stone, is it not also manifest in the built environment, the social environment, and the natural environment that contains and surrounds the giving of care? These places of caring are public monuments too; our long term care system and facilities nationwide are also expressions of who we are as a people. At the moment, the reflection in that broken mirror is not good.

## VI

If it does nothing else, joining into one thought the seemingly disparate ideas of dementia and the human good should increase our awareness of new possibilities for family, professional, and community caring.

Let us affirm the principle that in dementia there is a kind of agency that seems devoid of meaning and lacking in humanness, not because it really is, but only because we do not know how to interpret it. Agency and personhood of any kind eventually fade as dementia pursues its relentless course. Let us not hasten their demise prematurely through a kind of inadvertent hermeneutic and moral blindness, nor through a resource starved and distracted caregiving system that is unloving and merely custodial.

Bruce Jennings is Director of Bioethics at the Center for Humans and Nature, a research and educational institute that studies philosophical, ethical, and policy questions arising at the intersection of environmental policy, public health, and regional planning. It publishes an electronic journal, *Minding Nature*, which he edits. Mr. Jennings is also Senior Consultant and Fellow at The Hastings Center, a research institute where from 1991 through 1999 he served as Executive Director. He holds faculty appointments at the Yale University School of Public Health, Weill Cornell Medical College, and the New York Medical College.

E-mail: [brucejennings@humansandnature.org](mailto:brucejennings@humansandnature.org)

---

## Notes

<sup>1</sup> Stevens, "The Idea of Order at Key West," Yeats, "Sailing to Byzantium."

<sup>2</sup> I have explored the ideas presented here in greater detail in a number of previously published works. See Jennings 2000; 2001; 2006; and 2009.

<sup>3</sup> MacIntyre 1999; Kitwood 1997

<sup>4</sup> Kitwood 1993; Kittay 1999; Sabat and Harré 1992

<sup>5</sup> Bayley 1999; Bernlef 1988; DeBaggio 2002 and 2003; Cooney 2003; Davidson 1997; McGowin 2003; and Mitchell 1992.

<sup>6</sup> To fix ideas, I am working with the following general characterization of dementia. The various forms of dementia, Alzheimer Disease is the most common form, differ in some ways, but not so as to be significant for my discussion in this paper. Dementia is a progressive and degenerative brain disorder that gradually undermines cognitive function and emotional control. The disease lends itself to the mapping of various stages of impairment and dysfunction, although the manifestation of behavioral symptoms varies significantly among individuals. In addition to the loss of short-term memory and disorientation in relation to everyday activities, dementia also progressively manifests changes in the individual's personality, the onset of psychiatric conditions such as depression, paranoia, and hallucinations, erosion of executive functions regarding such things as personal hygiene, apparel, and social etiquette, and loss of self-control in the presence of strong feelings such as anger, frustration, or fear. Fine motor function, judgment, and physical response time may also be affected during the course of the disease.

<sup>7</sup> Damasio 1994; Souren and Franssen 1994.

<sup>8</sup> Jaworska 1999.

---

<sup>9</sup> Nussbaum 2000; 2006.

<sup>10</sup> Harré and Gillett 1994; Harré 1998.

### References

Bayley, John. 1999. Elegy for Iris. New York: St. Martin's Press.

Bernlef, J. 1988. Out of mind. London: Farber and Farber.

Cooney, Eleanor. 2003. Death in slow motion: my mother's descent into Alzheimer's.  
New York: HarperCollins.

Damasio, Antonio R. 1994. Descartes' Error: Emotion, Reason, and the Human Brain,  
New York: G. P. Putnam's Sons, 1994

Davidson, Ann. 1997. Alzheimer's, a love story: one year in my husband's journey.  
Secaucus, NJ: Carol Publishing Group.

DeBaggio, Thomas. 2002. Losing my mind: an intimate look ad life with Alzheimer's.  
New York: The Free Press.

DeBaggio, Thomas. 2003. When it gets dark: an enlightened reflection on life with  
Alzheimer's. New York: the Free Press.

Harré, Rom. 1998. The Singular Self. Thousand Oaks, CA: Sage Publications.

Harré, Rom and Grant Gillett. 1994. The Discursive Mind. Thousand Oakes, CA: Sage  
Publications, 1994.

- 
- Jaworska, Agnieszka. 1999. "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value," Philosophy and Public Affairs 28: 2 Spring 1999 , pp. 105-138.
- Jennings, Bruce. 2000. "A Life Greater than the Sum of Its Sensations: Ethics, Dementia, and the Quality of Life," in S.M. Albert and R. G. Logsdon eds. Assessing Quality of Life in Alzheimer's Disease. New York: Springer, 2000, pp. 165-178.
- \_\_\_\_\_. 2001. "Freedom Fading: On Dementia, Best Interests, and Public Safety," Georgia Law Review, 35: 2 Winter 2001 , 593-619.
- \_\_\_\_\_. 2006. "The Ordeal of Reminding: Traumatic Brain Injury and the Ethics of Care," Hastings Center Report, 37, no. 2 March/April 2006 : 29-37.
- \_\_\_\_\_. 2009. "Agency and Moral Relationship in Dementia," Metaphilosophy, 40: 3-4 (July), 425-437; reprinted in Eva F. Kittay and Licia Carlson, eds. Cognitive Disability and its Challenge to Moral Philosophy. New York: Wiley-Blackwell, 2010, pp. 171-182.
- Kittay, Eva Feder. 1999. Love's Labor: Essays on Women, Equality, and Dependency. New York: Routledge, 1999.
- Kitwood, Tom. 1993. "Towards a Theory of Dementia Care: The Interpersonal Process," Ageing and Society 13 1993 : 51-67
- Kitwood, Tom. 1997. Dementia Reconsidered. Buckingham: Open University Press, 1997.
- MacIntyre, Alasdair. 1999. Dependent Rational Animals. Chicago: Open Court Publishing Co., 1999.

---

McGowin, Diana Friel. 1993. Living in the labyrinth: a personal journey through the maze of Alzheimer's. New York: Delta Books.

Mitchell, Marilyn. 2002. Dancing on quicksand; a gift of friendship in the age of Alzheimer's. Boulder, CO: Johnson Books.

Nussbaum, Martha C. 2000. Women and Human Development. Cambridge: Cambridge University Press, 2000.

\_\_\_\_\_. 2006. Frontiers of Justice. Cambridge, MA: Harvard University Press, 2006.

Sabat, Steven R. and Rom Harré. 1992. "The Construction and Deconstruction of Self in Alzheimer's Disease," Ageing and Society 12 1992 : 443-461.

Souren, Liduin and Franssen, Emile. 1994. Broken Connections: Alzheimer's Disease, Part I, Lisse: Swets and Zeitlinger, 1994.