



## Re-inventing the Labyrinth: Self-Identity, Spirituality, and the Ethics of Intervention in the Lives of Persons Afflicted with Alzheimer's Disease

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The labyrinth that makes up the world of those afflicted with the irreversible, progressive dementia of Alzheimer's disease (AD), as well as their caregivers and professionals, can be a most troubling one. This is especially true today when the kind of person we are supposed to emulate is the rational agent who contributes to the economic, political, and social well being of the community. Those who make contributions are deemed to possess more worth than those who are unwilling or unable to make similar contributions, not only in terms of material worth, but also in regard to moral standing and spiritual well being. It is said that as the mental capacities, memories, and competencies of a lifetime slip away, so does the afflicted person's self-identity and, hence, any basis for moral stature and spirituality. Such a view may lead to paternalistic interventions in the lives of Alzheimer's sufferers, eventually leading to invasive medical procedures meant to prolong life without regard for its quality.

Is this labyrinth a necessary part of how we view this disease, or can it be re-invented so that the afflicted, the caregiver, and the professional can live as courageous and humane lives as possible in the face of AD? I believe the needed changes are already being made, beginning with how we understand personal self-identity. If we start from the conception of self as composed of memories that link an individual's past, present and future, then the Alzheimer's sufferer eventually loses his or her self-identity and becomes a "non-person." However, the self can be understood in a multitude of ways that are compatible with one another and that grant the Alzheimer's sufferer full personhood.

Personal identity can be understood as a reference point in space and time, and from which the person can express his or her identity through the use of first-person pronouns ("I" and "me"). Identity can be understood in terms of a unique set of mental and physical characteristics that change with the passage of time, as well as a set of beliefs about these characteristics. Personal identity can also be viewed as a social persona that is manifested in a dynamic interplay with other selves. Each of these identities can be an indicator of volition, emotion, relational interaction, and creative expression of the Alzheimer's sufferer. Identity is more than rationality and a sharp memory; the whole person is much more and merits care based on the enormity of need.

Morally acceptable intervention includes attending to a person's remaining capacities as well as comfort care in the final stage of the disease. Rituals and practices of beliefs that make up the practical expression of spirituality are important to many people, but extra care must also be taken to deal with spirituality itself, which is about human existence, relationships with ourselves and others, and self-transcendence, whether toward a god, higher power, or movement beyond the selfish confines of the ego. Given the significance of religiosity and spirituality to many Alzheimer's sufferers, these aspects of human existence should also be made available in a more holistic care regimen.

By de-emphasizing rationality and productivity, we can broaden the meaning of our humanity and the nature of human care and seriously work to develop a holistic ethic of dementia care that takes into account issues such as stigmatization, truth telling, self-determination, quality of life, genetic testing, and natural dying. The sooner we can re-invent the labyrinth and acknowledge that the Alzheimer's sufferer is a person with an identity, the sooner more humane care will be made accessible to some of the neediest in our society.



## Memory Ride 2004 Get Your Motors Running

Motorcycle riders get prepared! The 2004 Memory Ride will be on Saturday, October 9<sup>th</sup>. The riders will meet at Ameristar Casino Hotel in Council Bluffs at 8:30 a.m. for breakfast and travel a designated course. The registration fee for the event is \$15.00 per person or \$25.00 per couple.

There will be appetizers at Ameristar Casino Hotel starting at 5:00 p.m. (at the end of the Ride).

For more information on this event and to get a registration form, contact the Chapter's administrative office, (402) 572-3059 or toll-free at 1-800-309-2112.



### On-line Support Group

Do you live in a town not offering a Caregiver's Support Group? Are you a working caregiver and do not have time for an evening meeting? Are you unable to get to a support group?

Consider participating in the Midlands Chapter's on-line Caregiver's Support Group. It's a weekly group meeting on Wednesdays from 12:00 Noon – 1:00 p.m. CDT. Participants will be able to log-on and discuss caregiver issues. A Chapter staff member will facilitate the group.

The registration form and guidelines can be obtained from the Chapter website at [www.midlandsalz.org](http://www.midlandsalz.org). There is no cost for participating in this group.