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Alzheimer's and Related Disorders Interfaith Service held in Waco October 28, 2007
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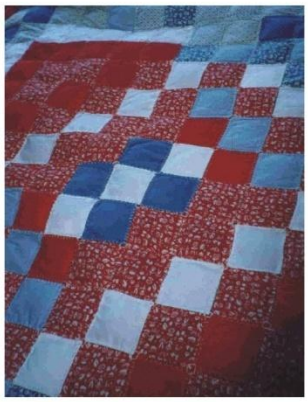
Reaching Out to the Spiritual Nature of Persons With Dementia
Annual Meeting of NCOA/ASA
Washington D. C.

03/27/08 at 2:00PM

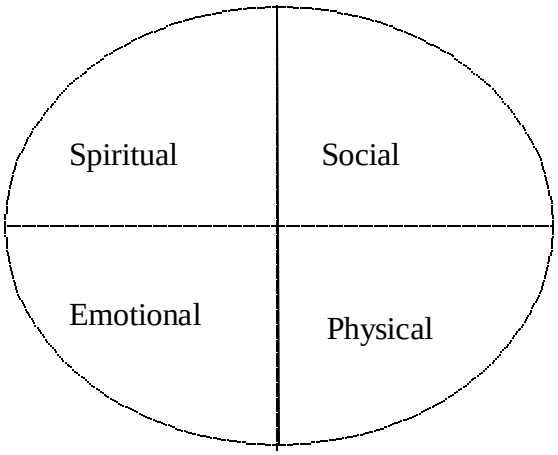
Does a person who has dementia have a soul? I have asked that question of persons across three continents and the answer is always, "Yes." So, if the person has a soul, then what is missing? The obvious answer is their memory and rational capacity. But this leaves open the question, what it is that makes up the essential nature of who we are as people? What is it that makes up a person and how does the spiritual fit into that? Is it her or his mind, or their soul or spirit? Just what is it that makes up the person of faith?

Numerous theologians and most sacred texts have taken on at least part of this question. What is it that makes us who we are? When dementia strikes, we are confronted with trying to understand not just the nature of the creation, but also the creator. In this brief paper I would like to take this on from the perspective of the person who has dementia.



Dementia here refers to Alzheimer's and all of the related dementias. While their impacts on physical memory are different, from a spiritual perspective, I would suggest that they are similar in that all impact the ability to imprint, store and retrieve memory and most will impact the capacity for rational thought. One way to interpret the impact of the dementias is to suggest that these diseases rob the individual of her or his story. From even before we are born the story of who we are is written. It is written in our families, it is written in the physical being that we are and that we become, this story is written all that we think, say or do. Stories are based on experiences.

The quilt can offer us a method of understanding life in the context of life experiences. If each patch on the quilt reflects an experience in our lives, then our lives are a patchwork of experiences. We can have patches in common with one another if we are a part of the same experience; however, the quilt itself is ultimately different as each person is unique in how they assemble the experiences in their lives. It can be argued that the fluff and backing of the quilt are those aspects of our lives that offer substance and flow through all of our lives. Such things as our spirituality or the sacred however it is defined in your life would make up these structural aspects of the quilt.



To employ this analogy, then for a person with dementia, the color of the patches may fade or even become unidentifiable to the owner of the quilt, but the quilt continues complete with the backing. If this is the case, then what is it that we need spiritually? The color has faded on the front, but maybe the spiritual aspect of the person remains intact. Often the challenge when working with a person who has dementia is in the ways we communicate with them. We understand how to ask a fellow believer, "tell me about what you believe, or words to that effect. Unfortunately that type of question assumes the respondent is cognitively capable of answering. The good news is that we are more than just what we know intellectually. Wholistic theory can help with this. According to Granger Westberg, the founder of Parish Nursing, we are whole persons. By that he meant that people are made up of physical, social, emotional and spiritual aspects of who they are. Both the strength and weakness of the wholistic model is found in how the various parts or aspects of the parson come together. Can they be separated? In Greek mythology, the body and spirit or soul were often separated in order for the soul to do battle in the underworld. If we can separate the soul or spirit, then it is a matter of finding new ways to communicate with it that doesn't involve intellect. If we cannot, then we continue to need to understand the person as a whole, the dementia in light of the spirit.

When looking at the spiritual aspect, we can see that there are three ways that human beings perceive their faith, or God. These are, intellectually, emotionally, and behaviourally. In other words we express our faith by what we ***know*** about God, ***feel*** about God and what we ***do*** for our faith in God. Once again, our knowledge is only one aspect of knowing God. For the Alzheimer patient, their knowledge of God is at best locked up in that irretrievable place that knowledge goes for persons with Dementia. But they will still express feelings when prompted by such things as music, singing, prayer or scripture verses. If you sit next to them in church and you kneel, they will kneel, if that is their tradition.

"Older adults need a vision, not only recreation,
Older adults need a dream, not only a memory.
It takes three things to attain a sense of significant being:
GOD,
A SOUL,
and **A MOMENT**.
And the three are always there.
Just to **BE** is a blessing,
Just to **LIVE** is holy."

Rabbi Abraham Heschel
White House Conference on Aging, 1971

Rabbi Heschel reflects on the need to see life as spiritual. Rabbi Heschel marched with Martin Luther King, Jr. His comment at the end of the march was that every step was a prayer. Reaching out to the spiritual is first and foremost an understanding that to "be is a blessing." For as long as the person with us, they are a spiritual person and should be related to as such.

Part of being a spiritual person is to be in a spiritual context; however that is defined by the senior. Singing the old songs, praying traditional prayers, going to traditional places of worship, as long as these are not new experiences for the senior, they can be spiritual. It can be a blessing to get a group of persons who are cognitively impaired together just to sing along songs from their childhood.

Alzheimer's disease and how it impacts the aged

Alzheimer's disease and the related disorders are not confined to the aged, yet are more common among the very old than any other age group. According to the Alzheimer's Association[1], about ten percent of persons over 65 have Alzheimer's disease, but more than fifty percent of persons over 85 have it. Thus, the types of cognitive disorder commonly found among older adults are not simply the product of aging. Rather, they are the product of over 150 possible diseases and/or traumatic events. Since dementia is most likely to be found in the aged, however, aging *becomes the environment* for these diseases, not the cause. Aging itself is a journey. As such it is not without its bumps and bruises. To understand the nature of our own aging, it may be helpful to think about the simple equation found in Box 1. The difference between an older adult and a younger one is a matter of amount, the amount of time and the amount of experience. Hebrew scripture tells us that wisdom is with the aged. (Sirach 25:4) Yet it also suggests that not all aged persons are wise. Wisdom is the product of insight.

Time + Experience = Aging

Box 1

The environment of the person with dementia is also a reflection of the basic nature of our communication skills. Most people do not stop to realize how dependent on the ability to communicate and on memory our skills or interpersonal relations are until we encounter a person with a profound cognitive impairment. Our skills for listening, gaining insight into life's experiences, our basic ability to understand the older adult is based on cognitive abilities that are weakened and ultimately lost to the Alzheimer patient. Caregivers and members of the community need to learn new skills for support of this special group of people.

Stages According to the Alzheimer's Association

Stage 1: Early Stage
Stage 2: Mid stage
Stage 3: Final stage

Box 2

Cognitive disorders, such as Alzheimer's disease, affect the entire functioning of the brain. From the perspective of the non-medical practitioner this means that both memory functions ***and*** the ability to use rational thinking are impaired. Alzheimer's disease follows a progression of cognitive debilitation that can be traced in stages. (See Box 2) As the stages progress, the individual slowly loses his or her ability to think through even the simplest tasks in everyday living. The affected senior is unable to talk about his or her faith or to express the nature of the self. He or she is even unable to say "thank you for visiting."

Functional types of memory

- Recognition
- Short term
- Long term
- Second hand

Box 3

The role of memory in the nature of who we are seems to reflect its capacity to contain the history of the person. Where there us no memory, there seems to be no history. This is one of the significant losses felt by families. To not be able to ask one's parents who Uncle Fred was, when they receive a death notice, or even to help our children write reports for school is a significant loss. When a person comes in for counseling, it is as if he or she comes carrying a bag with two handles filled with memories. As

[1] Association, Alzheimer's. Basic Facts and Statistics About Alzheimer's Disease. 2003. Alzheimer's Association. September 10, 2003.

their stories or memories are shared, it is as if he or she gives one handle of the bag to the listener. Normally, when the dialogue ends, that handle is given back to the speaker to carry alone. However, in the case of the person with dementia, in the beginning he or she can share their sack filled with stories, but as the disease progresses, not only does he or she give one handle over to the listener, but he or she then gives the other one as well. A spiritual crisis for persons with dementia is, "who will carry my story, when I am no longer able to do so?"

One of the sad things about our society is that we don't fully understand how to communicate with or empathize with persons who have cognitive impairments. To have a family member who has dementia is often referred to as "the long good - bye." Another way to talk about it is in terms of anticipatory grief. If the task of the caregiver and family member is to say good - by, then too often we externalize and distance ourselves from the source of the pain. Often the source of this pain is the individual with dementia. Clearly this is true socially. Many families as they care for a cognitively impaired relative become isolated themselves. Often religious traditions offer rituals and rules for how we grieve the death of a relative, but less clear in our various traditions is any prescription for living with and caregiving for a person with dementia. On the other hand, if the task is to let go of those aspects of the person that he or she can no longer handle, but to appreciate what he or she can, then caregiving is a different task. Maybe we need more "right" brained approaches to meeting, greeting and appreciating a person who has dementia. Approaches that honor the person, yet do not ask more of him or her than he or she can provide. Sometimes that means laughing with the person. Sometimes that may mean appreciating the creative and spiritual aspects of the person.

Reaching out to the Soul

Ministry with older adults who suffer from cognitive impairment begins with changing the assumptions with which we go to church. Worship leaders tend to assume the parishioners have the capacity to fully understand what is said in the service.

Principles of Working with Persons who have Alzheimer's disease[2]

1. Gain attention: Initial talks with cognitively impaired persons should begin by gaining their attention.
2. Speak with, the way you want to be spoken to: Speak to the client in a manner that you would like to be spoken to; as an adult and with respect. Confused persons do have feelings.
    a. Not children - speak as adults
    b. They understand your feelings better than they do
3. Two Step requests - no more: When asking the client to do something, remember to be conscious of the number of steps in the request. Most confused persons can handle no more than two steps.
4. Need self esteem: Like everyone else, confused seniors need to feel O.K. about themselves. However, this may be more difficult to do!

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[2] Source: Brown, M.J., Ellor, J.W., "An Approach to Treatment of the Symptoms Caused by Cognitive Disorders in the Aged," Salud Publica De Mexico, May-June 1981, Vol. 23, No.3, PP. 259 - 268.

5. The person is shadow of former self: It is sometimes helpful when working with the client's family to think of the person as being a "shadow of his or her former self."
6. Significant other important: People who are significant to the cognitively impaired person are an important factor in the care and treatment of the client.
7. As you work with the person, identify their strengths, not just their weaknesses. Work to help the person maintain the highest level of behavior.

Bibliography

- Brown, M., & Ellor, J. W. (1981). An Approach to the Treatment of the Symptoms Caused by Cognitive Disorder in the Aged. Salud Publica, 23(3), 259.

- Association, Alzheimer's. Basic Facts and Statistics About Alzheimer's Disease. 2003. Alzheimer's Association. September 10, 2003

- Bird, Michael. "Dementia and Suffering in Nursing Homes." The Journal of Religious Gerontology 13.3/4 (2002): 49-68.

- Bryden, Christine, and Elizabeth MacKinlay. "Dementia - a Spiritual Journey toward the Divine: A Personal View of Dementia." Mental Health and Spirituality in Later Life. Ed. Elizabeth MacKinlay. Binghamton: The Haworth Press, 2002.

- ---. "Dementia - a Spiritual Journey toward the Divine: A Personal View of Dementia." The Journal of Religious Gerontology 13.3/4 (2002): 69-76.

- Ellor, James W. "Celebrating the Human Spirit." God Never Forgets. Ed. Donald K. McKim. Louisville: Westminster/John Knox Press, 1997.

- ---. "The Challenge of Alzheimer's." The Clergy Journal 71.8 (1995): 3-6.

- ---. "Love, Wisdom, and Justice: Transcending Caring." God Never Forgets. Ed. Donald K. McKim. Louisville: Westminster/John Knox Press, 1997.

- Ellor, James W., and Michelle Rizzo. "Cognitive Functioning of the Older Ostomate." E. T. Journal 5.2 (1978): 14-15.

- Ellor, James W., John Stettner, and Helen Spath. "Ministry with the Confused Elderly." Journal of Religion and Aging 4.2 (1987).

- Ellor, J., Kimble, M., McFadden, S., Rost, R., & Seeber, J. (2000). Ministry with Older Adults in the Church. Chicago: Evangelical Lutheran Church of America.

- Ellor, J., McFadden, S., & Sapp, S. (1999). Tenth Anniversary Issue: Aging and Spirituality. San Francisco: American Society on Aging.

- Ellor, J., Netting, E., & Thibault, J. (1999). Understanding Religious and Spiritual Aspects of Human Service Practice. Columbia: The University of South Carolina Press.

- Goldsmith, Malcolm. "Through a Glass Darkly: A Dialogue between Dementia and Faith." Aging Spirituality and Pastoral Care: A Multi-National Perspective. Eds. Elizabeth MacKinlay, James W. Ellor and Stephen Pickard. Binghamton: The Haworth Press, 2001.

- ---. "When Words Are No Longer Necessary." Aging, Spirituality and Pastoral Care: A Multi-National Perspective. Eds. Elizabeth MacKinlay, James W. Ellor and Stephen Pickard. Binghamton: The Haworth Press, 2001.

- Hide, Kerrie. "Symbol Ritual and Dementia." Journal of Religious Gerontology 13.3/4 (2002): 77-90.Kimble, M., McFadden, S. H., Ellor, J. W., & Seeber, J. S. (1995). Aging, Religion and Spirituality: A Handbook. Minneapolis: Fortress Press.

- MacKinlay, Karen. "Listening to People with Dementia: A Pastoral Care Perspective." Journal of Religious Gerontology 13.3/4 (2002): 91-106.

- McKinlay, E., Ellor, J., & Pickard, S. (2002). Aging, Spirituality and Pastoral Care in the Twenty-First Century: A Multi-National Perspective. Binghamton: The Haworth Press.

- Netting, F. E., & Ellor, J. W. (In Press). Faith Based Initiatives and Older Adults. Binghamton: The Haworth Press.

- Tobin, S. S., Ellor, J. W., & Anderson-Ray, S. (1986). Enabling the Elderly: Religious Institutions within the Community Service System. Albany: State University of New York Press.

Rev. James W. Ellor, Ph.D., D. Min., LCSW, DCSW
Editor: Journal of Religion, Spirituality and Aging
Professor: School of Social Work
Director: Center for Gerontological Studies
Baylor University
One Bear Place # 97320
Waco, Texas 76798-7320
James_Ellor@Baylor.edu

Steps to Developing Worship with the Cognitively Impaired Elderly

Based on: Ellor, J. W., Stettner, J., & Spath, H. (1987). Ministry with the confused elderly. *Journal of Religion and Aging, 4*(2).

I. The Environment

A. Define a specific location in the facility, free from other noise and distraction.

B. Try to make the setting look like a church or synagogue.

1. Put a cloth over a table.
2. Use banners, candles, etc. consistent with the faith tradition of the residents.
3. Worship leaders should wear robes, etc. as if in normal religious congregation.

C. Use a piano or other musical instruments as possible. Tape recordings can be confusing.

II. The Service

A. Begin with a list of the elements of worship that would be used in your facility for the Non-confused residents. (Elements include music, prayer, etc.)

B. Work with a group of non-impaired seniors to determine which of the possible elements of worship they have memorized. (For example, which hymns or prayers have been memorized?)

C. Design all elements of worship to be participatory. (Any element of worship that cannot be actively participated in must be left out, for example the sermon!)

D. Try out the service on the non-confused residents to see if it is of interest.

E. Hold services on Sunday, or the traditional evening for the predominant religious group.

III. Worships leaders

* Develop a committee of family members of the confused residents to help lead worship; it may also be useful to include some of the CNA staff.

Suggested Order of Worship for Methodist Congregations

Call to Worship
Hymn
Confession of Sins
Assurance of Pardon
Old Testament Reading
Apostles' Creed
Hymn
Pastoral Prayer & Lord's Prayer
New Testament Reading
Hymn
Benediction

Suggested Hymns and Scripture for Methodist Congregations

Hymns

Rock of Ages
A Mighty Fortress
I Love to Tell the Story
Old rugged Cross
Blessed Assurance
How Great Thou Art
Amazing Grace
In the Garden
What A Friend We have in Jesus
We've a Story to Tell
Till We Meet Again
Onward Christian Soldiers
Sweet Hour of Prayer
Stand Up! Stand Up for Jesus
Trust and Obey
Holy, Holy, Holy
Come Thou Almighty King
Breathe on Me, Breath of God
Faith of Our Fathers

Bible Verses

Genesis 1:1-2
Exodus 20:2-17 (Ten Commandments)
Deuteronomy 6: 4-9
Psalms 8, 23, 100, 91, 104
Isaiah 61: 1-2
Matthew 5: 3 - 12 (Beatitudes)
Luke 1: 46-48; 2: 29-32
John 1:1-5; 3:16; 6:35; 8:12; 14:1-3

Suggested Hymns and Scripture for Baptist Congregations

Hymns	**Scripture which most seniors have memorized**
Amazing Grace	Psalm 23
Holy, Holy, Holy	Genesis 1:1-2
Just as I am	Psalm 100
What a Friend we have in Jesus	John 3:16
Old Rugged Cross	John 14:1-3
Jesus Loves Me	Romans 8:28
Blessed Assurance	Psalm 104
When the Roll is called up Yonder	John 3:3
Victory in Jesus	Romans 6:23
Mansion on the Hilltop	Romans 8:21
There is Power in the Blood	Matthew 5:3-12
I Love to Tell the Story	Proverbs 3:5-6
I'll Fly Away	Isaiah 41:10
There is Power in the Blood	II Chronicles 7:14-15

Go to www.baylor.edu/gerontology (Older Adult Ministries Senior Programs) for a more comprehensive list of suggestions.