

VOLUME 7 NUMBER 2 Spring 2010

*An Inter-Lutheran Journal
for Practitioners and
Teachers of Pastoral Care
and Counseling*



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THE PURPOSE OF CARING CONNECTIONS

Caring Connections: An Inter-Lutheran Journal for Practitioners and Teachers of Pastoral Care and Counseling is written by and for Lutheran practitioners and educators in the fields of pastoral care, counseling, and education. Seeking to promote both breadth and depth of reflection on the theology and practice of ministry in the Lutheran tradition, *Caring Connections* intends to be academically informed, yet readable; solidly grounded in the practice of ministry; and theologically probing.

Caring Connections seeks to reach a broad readership, including chaplains, pastoral counselors, seminary faculty and other teachers in academic settings, clinical educators, synod and district leaders, others in specialized ministries, and—not least—concerned congregational pastors and laity. *Caring Connections* also provides news and information about activities, events, and opportunities of interest to diverse constituencies in specialized ministries.

Credits: Photos pp. 5, 11, 11, 17, 20, cover, stock.xchng

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Electronic Subscriptions: Please visit www.caringconnectionsonline.org and click on “Click here for free subscription” to receive automatic notification of new issues.

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Editorial

Welcome once again to *Caring Connections*! This Spring, 2010 issue draws our attention to the challenging ministry with people suffering with various kinds of dementia. This is a topic dear to my own heart, since my mother died in 1999 with what the doctor diagnosed as “age-related dementia.” He distinguished this from the better known Alzheimer’s Disease by using the analogy, “Alzheimer’s Disease is a slow, steady slide into dementia; age-related dementia is more like going down a flight of stairs, with periods of stability followed by a sharp, sudden decline in cognition.” Because of my work on the Dementia Unit in The Village at Manor Park, in Milwaukee, I was familiar with the devastating effects of both kinds of loss. I am also familiar with some of the powerful resources we pastoral care providers have for working with people with dementia.

In this issue we have gathered articles from a number of people who share with us their experience and reflections on ministry to people suffering with dementia. You’ll also find resources for your ministry as well. Gary Sartain, Director of the North-Central Region of ACPE, Inc., shares “A Theology for Alzheimer’s and Related Dementia.” Donna Erickson, a retired chaplain in long-term care settings, has updated a paper she wrote in 1994 as part of her doctoral studies, titled, “Search for the Memory of God.” Another retired long-term care chaplain, Don Koepke, offers us “Engaging the Spirit of Persons with a Dementia.” In between these three substantial articles we have included two reflective pieces. Anna Bliss shares “Fading,” a brief reflection on her father, who died after suffering from both dementia and macular degeneration. Anna read this piece at her father’s interment. Anne Burton submits “Notes in the Red Silk Notebook,” drawn from the journal she wrote while her husband’s dementia increased.

We think the articles in this issue of *Caring Connections* will engage both your head and your heart. We hope they will also inspire you in your own ministries with God’s people who suffer with dementia, and with their family members as well. In addition to these articles, we want to draw your attention to three additional resources you might find helpful in your ministry with people with dementia. They are:

Tom Kitwood, *Dementia Reconsidered: The Person Comes First*, Reconsidering Ageing [sic] Series, ed. Brian Gearing (Philadelphia: Open University Press, 1997).

Stephen G. Post, *The Moral Challenge of Alzheimer*

Disease: Ethical Issues from Diagnosis to Dying, 2d ed. (Baltimore: Johns Hopkins University Press, 2000).

David B. McCurdy, “Personhood, Spirituality, and Hope in the Care of Human Beings with Dementia,” *Journal of Clinical Ethics* 9, no. 1 (Spring 1998): 81-91.

We want to hear from you if you find these books and articles helpful. Kevin and I welcome *any* responses you might have after reading these contributions. Perhaps you have a poignant ministry moment of your own that you would like to share. If so, send us an email (either Chuck at cweinrich@cfl.rr.com or Kevin at kevin.massey@elca.org). We’ll include your thoughts in a subsequent issue.

Have you read the brochure you received a month or so ago about **ZION XIV**, the triennial gathering of Lutherans in Specialized Ministry settings? More importantly, have you sent in your registration? It looks to be an exciting gathering. Be sure to read the details on the conference in the “News, Announcements and Events” segment of this issue. Make your plans NOW to join us in Atlanta, Georgia on October 21-24, 2010. We’ll write more about it in the next issue of *Caring Connections* as well.

We want to remind any of you who are Lutherans in training to become a Chaplain, Pastoral Counselor, or Clinical Educator, that the **Give Something Back** Scholarship Fund — at this time — has \$3000.00 available every six months for those Lutheran brothers and sisters who are in need of financial assistance as they journey through their professional training. If you are interested in obtaining more information, contact either the ELCA “Ministry of Chaplaincy, Pastoral Counseling, and Clinical Education” office, Theresa.Duty@elca.org or send your grant request to the LCMS office of “Specialized Pastoral Care,” Judy.Ladage@lcms.org.

And, as we always write, if you haven’t already done so, we hope you will subscribe online to *Caring Connections*. Remember, **subscription is free!** By subscribing, you assure that you will receive prompt notification when each issue of the journal appears on the *Caring Connections* website. This also helps the editors and the editorial board to get a sense of how much interest is being generated by each issue. We are delighted that the numbers of those who check in is increasing with each new issue. You can subscribe by clicking on the subscription link on www.caringconnectionsonline.org, or by following the directions given on the masthead (p. 3), or in larger print on page 27.

Call for Articles

Caring Connections seeks to provide Lutheran Pastoral Care Providers the opportunity to share expertise and insight with the wider community. We want to invite anyone interested in writing an article to please contact the editors, Rev. Kevin Massey and Rev. Chuck Weinrich.

Specifically, we invite articles for upcoming issues on the following themes.

Summer 2010 “Parish Nursing”

Fall 2010 “Pastoral Care and Addictions”

A Theology for Alzheimer's and Related Dementia

Even life's negatives, even a whole world groaning in travail (Romans 8:22), even something as vicious and damnable as Alzheimer's disease, cannot prevail against the power and love of God!

Stephen Sapp, Chair of the Department of Religious Studies at the University of Miami, says that how one deals with life depends ultimately on how one understands God, and that is what theology is about: "Theology — one's understanding of God — makes a difference in the ways human beings live with one another, in the ways they deal with the pain and suffering of this life, in the joy that comes from service to those in need, and in the ways they approach their own death and the death of others."

Krister Stendahl, the recently deceased Swedish theologian and New Testament scholar, said: "To do theology is to try to see things as God sees them — a task so obviously arrogant and oversized that we can only do it playfully — as children. But to children, play is serious and creative, and it does something to their growth."

Henri Nouwen, the Dutch-born Roman Catholic Priest and writer whose many works are well known to us in the pastoral care arena, claimed that the original meaning of the word "theology" was "union with God in prayer". He went on to say: "It is important to reclaim the mystical aspect of theology so that every word spoken, every advice given, and every strategy developed can come from a heart that knows God intimately."

It is out of these understandings that I will attempt to lay some foundation for a theology for Alzheimer's and related dementia, and reference additional literary resources that will allow parties that are interested in a more sustained theological engagement to delve more deeply.

David Keck, in his excellent book, *Forgetting Whose We Are, Alzheimer's Disease and the Love of God* (1996: Abingdon Press, Nashville, TN – ISBN 0-687-02088-3), writes from his own experience with a mother who had Alzheimer's that the disease confronts those who encounter it in any significant fashion with the clear limitations of their human powers (by constantly reminding them of our common weakness), as well as their own radical finitude (by posing a constant reminder that we all die). He goes on to say that Alzheimer's challenges all our assumptions about language, meaning and humanity itself because, as the disease progresses, it "seems to be all about the deconstructing of narrative, the breakdown and subversion of personal story."

This view is echoed by Glenn Weaver, Professor of Psychology and Religion at Calvin College, who



says "The dissolution caused by Alzheimer's seems to be a reversal of the ordering process of creation and a return to the chaos of the deep; an inversion of the Biblical narratives" ("Senile Dementia and a Resurrection Theology": *Theology Today* 42 (1986): 447).

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Alzheimer's is disintegrative, non-redemptive, of uncertain etiology, and inexorably lethal. This combination is what makes it so challenging theologically both from an ontological and a spiritual perspective.

So, where to begin? It seems logical to first explore what it means to be created “in the image of God,” since the *imago Dei* was introduced to us already in the core creation stories found in the Hebrew Scriptures. Genesis 1:28 and 2:19 and Psalm 8:5-6 all suggest that creation in the image of God confers uniqueness and dignity to human beings by virtue of a special relationship with God and their pre-eminent place of authority in the created order. Old Testament anthropology concentrated on human beings in the totality of their existence. There is an animating principle — *nephesh* — that is an integral part of human beings, and it is this principle that confers *imago Dei*. Body and soul or flesh and spirit were not separate entities for the early Hebrews. They were interdependent elements that were both necessary for a human being to exist.

For many in the Christian tradition, however, the understanding of what it means to be created *imago Dei* has centered on soul, since the image could hardly be corporeal. And the thinking, rational element of soul became the central locus. Reason, memory, consciousness, the moral conscience, the will, the capacity to love — the mental life of a person — these were its distinguishing features. Creation in the image of God came to refer to our ability to reason, to produce complex language, or to relate to one another and to God in ways mediated by our intellect.

This view was reinforced by the rationalism of the enlightenment, and has become an integral part of our American folk belief system, which — deeply rooted in capitalism and individualism as it is — believes at core, it seems to me, that rationality and productivity (measured almost exclusively in economic terms) are what confers worth.

This prevalent, popular view is highly problematic for persons with Alzheimer’s and related dementias. It is not hard to determine what such a society’s opinion will be of someone who is judged to have lost individuality, productivity, and rationality to dementia! It is therefore imperative that we put forward a theology that confronts our hyper-cognitive, hyper-active society’s move toward the claim that “I am” equals “I am able to think and do.”

Fortunately, there are theologians who have paved the way, who have refused to see *imago Dei* or the presence of soul as correlated with mental capacity or the ability to produce.

One of the first of these is Augustine, who referred to human beings as *terra animate* — animated earth:

To earth you will go (Genesis 3:19) means, we may be sure, on losing your life you will go back to what you were before you received life. That is, when the breath of life has left, you will be what you were before you received that breath, for, as we know, it was into a piece of earth that God breathed the breath of life when man was made a living soul.

The emphasis for Augustine was on God’s action, and there is no indication that he equated *animate* with the mind, the cognitive faculties, rationality, self-awareness, or anything of the kind. Rather, it was exactly what the Hebrew says it is, the “force of life.”

It is imperative that we put forward a theology that confronts our hyper-cognitive, hyper-active society’s move toward the claim that “I am” equals “I am able to think and do.”

Thomas à Kempis is another case in point with his *Imitation of Christ*, in which he writes frequently of the immediacy of the God-soul relationship, referring to God as “zealous lover of souls” and to Christ as “the spouse of the soul, physician of the soul, and guardian of the soul.” “Until your light illuminates my soul, I am dull earth, formless and empty.” “All things are in your power (Christ), and you always long to bring souls to perfection.” What emerges from a careful discernment of à Kempis’ work is the significance of what might be called “the passive voice soul,” the soul as an object of God’s work that desperately needs to be acted upon. As à Kempis writes, “Unless a man’s soul is raised...and wholly united to God, neither his knowledge nor his possessions are of any value.” à Kempis sees the soul teleologically — it cannot be considered apart from its final resting place. Until we get there, we are reminded that even in a demented person, God’s Spirit can be present to the soul.

Thomas à Kempis affirms the truth of Psalm 62:1 (which might be considered the demented person’s creed and hope):

“For God alone my soul waits in silence; from him comes my salvation.”

Building on the above, Gilbert Meilaender, in “Terra es animate: On having a Life” (Hastings Center Report 23 — July/August, 1993) points out:

Even after a person ceases to be aware of the part in the story that is his or her life, that story certainly continues physically in the body’s ongoing ingestion and utilization of nourishment, in its struggles against injury and infection, and simply in the ongoing presence of the body that has always been the location of the ‘I’ that loved ones and friends have known. It continues interpersonally in their (loved ones and friends) interactions with the person — if only as his or her caregivers — and even if his or her contributions to the relationship are limited or have ceased altogether. And it continues socially by virtue of the fact that

until the totality that the Western religious tradition affirms is really the person ceases to be, that person does still occupy a place in the community, however limited. Thus even when one's rational capacities fade or fail completely, the 'I' that consists of much more than those capacities continues to exist — diminished to be sure, but still worthy of the dignity and respect due to all those who are created in God's own image.

John Calvin argues that the *imago Dei* must be understood teleologically and eschatologically, "for it is only shadowed forth in man until he reaches perfection." The image of God is "man's destiny in God's gracious intention. It is the original truth of his being which is also future." Calvin argues that no human being reflects God's image perfectly; that possibility was lost in the original disobedience of Adam and Eve. The atoning work of Christ, however, restores at least the possibility of doing so, but only when humans reach perfection in the hereafter. In keeping the focus clearly on God and God's glory, Calvin's theology affirms that even in a cognitively impaired state, the individual can still reflect that glory, which is surely cause for hope.

Any assumption that a person's capacity to relate to God is lost when he or she loses cognitive function sells God short! The initiative is with God for all of us. David L. Miller said it well in the September 1994 *Lutheran*: "Hope has to do with the presence of God, not the absence of struggle."

Furthermore, if one accepts the central Christian doctrine that the death of Jesus Christ alone is sufficient to restore the broken relationship between human beings and their Creator, then one must acknowledge, as Martin Luther asserted, one's absolute dependence on the unmerited and freely given grace of God. If we do that, then we will be careful about devaluing those with cognitive or functional infirmities that lead to their loss of independence out of the realization that in God's eyes — the scale that really matters — we are just as dependent as they are! And, if we can acknowledge that we are totally dependent throughout our lives on the creating, redeeming, and sustaining God, then perhaps it will be easier to accept increasing dependence upon other human beings ourselves as we age and face the infirmities that accompany it.

In Romans 3:22-24, Paul writes: "There is no difference, for all have sinned and fall short of the glory of God, and are justified freely by his grace through the redemption that came by Christ Jesus." For Paul, no one can claim superiority over anyone else — no more on the basis of better cognitive function than on other grounds like race, wealth, or supposed greater moral virtue — because all stand on common ground, having been redeemed by Christ. In this way Paul expands the equality of all human beings implied by their shared creation *imago Dei* to include a distinctively Christian element: As beings created in God's likeness gives dignity and worth to all human

beings, even more so does the willingness of God's Son to die for them!

Another avenue worthy of exploration is the Judeo-Christian concept of community. The biblical religions assert in numerous ways that God sees human beings not as disconnected individuals, but rather as social-historical beings who are undeniably linked with others, living in community and changing over time in ways over which they

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do not always have control. In recognition of this, ethicist Lisa Cahil (*Between the Sexes: Foundations for a Christian Ethics of Sexuality*, 1985: Philadelphia: Fortress Press) claims, "the horizon against which all moral activity is to be evaluated is the communal life as body of Christ in the world." This is certainly what Paul asserts in 1 Corinthians, chapter 12.

In this regard, the idea of "corporate memory" has merit, particularly if we do a word play with "remember" by inserting a hyphen in it: "re-member." As people lose their cognitive capacities in our hyper-cognitive society, they tend to be shunted to the periphery, to have their very humanity questioned, certainly to be treated with less than the full dignity that the theology of *imago Dei* would ascribe to them.

But the community of faith, the body of Christ of which people without cognitive abilities are an organic part, is called to remember them by continuing to treat them like those whom God sees as beloved children. When this happens, the community "re-members" them, in the sense of bringing them back into the human community, refusing to let them be cast aside and forgotten, which would be, in effect, to *dis-member* them (and ourselves) as the body of Christ.

As the elements of memory, personality, and the ability to think things through rationally slip away, a person with dementia needs fellow travelers who can share the journey, offer guidance along the road, and eventually become the container for those memories that they can no longer access for themselves. And, of course, memories are held by more than an individual. They are shared by and with those we care about, as well as being contained in the records, photographs and other memorabilia we accumulate. It is important for us as pastoral caregivers to remember that, and help family and friends realize that they are not helpless, but rather have a vital role to play as a repository of memory. Even more important from a theological standpoint is the need

for us to proclaim that these memories are shared by God, who does not forget, even if we cannot remember.

In *Memory and Tradition in Israel*, Brevard Childs observes that for the Hebrew people “not to be remembered” is not to exist (In Psalm 88, the person whom God has forgotten “has no strength, is already in the grave...”). The encouraging news of both the Old and New Testament is that God does remember. In fact, God’s mercy and God’s memory are really one and the same.

In your distress, when all these things have happened to you in time to come, you will return to the Lord your God and heed him. Because the Lord your God is a merciful God, he will neither abandon you nor destroy you; he will not forget the covenant with your ancestors that he swore to them (Deuteronomy 4:30-31).

The Hebrew Bible suggests over and over again that because of its forgetfulness, Israel seems constantly in danger of complete dissolution. Only God’s memory prevents total destruction. In fact, it does more than that. God’s remembering implies providential, salvific activity. Furthermore, God helps people remember, as God has commanded God’s people to wear tassels...to mark door posts...to drink wine and eat bread. We need to follow God’s example and create ritual that helps dementia patients and their caregivers remember. The vicarious elements in theological reflection and church practice need particular emphasis. As the community accepts the responsibility of believing for a newly baptized infant in our tradition, so, too, at the end of life must the church accept this task for those in end-stage dementia.

Henri Bergson’s concept of “*durée*” (the subjective perception of space-time), which was highly influential for H. Richard Niebuhr’s *The Meaning of Revelation*, seems to be very applicable here. It suggests that, because of the action of the Holy Spirit, the past as we commonly understand it never ceases to exist. Through osmosis the past flows into the present and comes to interpenetrate it with power. It gnaws and impinges on the present, often without our being aware of it. “If I say, ‘I will not mention him, or speak any more in his name,’ then within me there is something like a burning fire” (Jeremiah 20:9). Caregivers can be helped to see that their role is not only to give care, but also to bestow a kind of immortality by recalling for others around them what the person with dementia no longer can recall, in order to strengthen the remembering capacity of that person, and to keep his or her role in the story of the community alive in the corporate memory.

We do this regularly for the dead; why can’t we do it for the living? The reason is that in many ways it is easier to experience the death of one that we care about, since with death, the history of this person in this life ends. For the Alzheimer or dementia patient, history seems to continue in a way that family and

friends feel is contradictory to the nature of the previous relationship. In the grief surrounding death, there is one loss and one task—changing our relationship with the person from one of presence to one of memory. Living with a person with dementia means facing loss after loss, and the constant and exhausting reframing of the relationship over and over again. And caregivers are still left with the final task, after having already been depleted by the process.

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We need to help them all — those who have dementia and those who suffer along with them — find hope and meaning on the journey, if we are to lessen the burden. Stephen Post, Director of the Alzheimer Center at Case Western Reserve University, gives us a starting point when he reminds us that persons possess more than memory and intellect. They also have emotion, relationship, imagination, will and aesthetic awareness. He asks, “If a deeper experience of life could be realized by ourselves through greater awareness of touch, music, human presence, love, smell, color, play, laughter, nature and so on, what could this mean in the lives of those with dementia?” And Deborah Everett reminds us, “The person suffering from senile dementia does not stop needing what made him or her happy in the past. Only memory and communication are affected. Every person needs to feel secure, to have dignity, to give and receive love and to feel affection.”

Matthew Fox, a proponent of creation-centered theology, reminds us that the holy and the sacred are experienced and expressed in much broader ways than merely through the cognitive faculty. They are also experienced and expressed through the senses. In *The Care of the Soul*, Thomas Moore invites us to stop thinking of the person affected by dementia as needing to be fixed, and focus instead on what he calls the yearnings of the soul, remembering that what nourishes the mind is not necessarily the same as what nourishes the soul. The cognitively impaired still have emotions, imagination, a will and moral awareness far into the disease process. Feelings retain importance and influence long beyond the time when they can be understood or articulated — vital wellsprings from which we experience life’s

meaning. By focusing our personal interventions in these alternate areas, and supporting and equipping caregivers to do the same, we will meet the needs of the spirit and bring hope into the chaos. But if we are going to do so, we need to reframe this ministry into being a mystery to be experienced rather than a problem to be solved.

The sufferings of Alzheimer's disease and related dementias frequently lead people to ask where God is in all of this, and why God allows this disease to happen. The attributes and qualities usually ascribed to God — goodness, mercy, and omnipotence — seem to be unusually absent. This is where the theology of the cross can be so helpful. The Church can presume to speak to these situations because her very existence is a result of the desolation, despoiling, and twisting of God's own body. On the cross God shows us that being God-like is not so much a matter of wielding power over creation as it is entering into the powerlessness of crucifixion with a suffering and redeeming love. This moves us from despairing that there is no rescue, to finding comfort in the fact that God accompanies us in our weaknesses and diminishments all the way to death — and then acts to take away its sting. As Martin Luther King Jr. said, "We must accept finite disappointment, but we must never lose infinite hope." Even life's negatives, even a whole world groaning in travail (Romans 8:22), even something as vicious and damnable as Alzheimer's disease, cannot prevail against the power and love of God!

Caregivers should be encouraged to study the Isaiah apocalypse, as recorded in Isaiah chapters 24-27. Its evocative language is a good analogy for the dementia sufferer and his or her mind. Desolation, twisted surfaces (as in brain plaques), pollution, chaos, the pit and the snare, the crying out — all of this resonates with caregivers. The language is biblical but the reality is contemporary. Although Isaiah laments primarily social and political disasters while these caregivers cry over family disasters, the experience is similar, the Lordship of God over this earth is in question. In the midst of that Isaiah declares, "From the ends of the earth we hear songs of praise, of glory to the Righteous One." How is Isaiah able to present such joy amid the ruthlessness of the present? He affirms the triumph of the Creator over humanity's self-destruction: "He will swallow up death forever. The dead shall live; their bodies shall rise. O dwellers in the dust, awake and sing for joy!"

Marcus Borg, *Meeting Jesus Again for the First Time* (New York: Harper, 1994), talks about biblical macro-stories that have direct application to the pastoral care of persons with dementia. They are wilderness and exile. To these can be added chaos and waiting.

To the chaos and confusion of the dementia person's world we can bring the reminder that the first scene of the scriptures is about drawing order and meaning out of chaos: "Now the earth was formless and empty, darkness was over the surface of the

deep, and the spirit of God was hovering over the waters. And God said, 'Let there be light'..."

We can also bring the reminder to people feeling lost on the journey that, during their forty years of wandering in the desert, God continually led and

We need to trust that God will find avenues to offer God's presence to these wilderness wanderers, just as was done for Israel — and we need to be watchful for and facilitate these avenues as best we can.

guarded the lives of the Israelites, offering presence and care in tangible and concrete ways. There were resources from nature like the pillar of fire, manna from heaven, and sacred objects like the Ark of the Covenant and a tent for meetings. In the midst of their wilderness wanderings, God met Israel through means of grace that became ritualized and managed through the priesthood — ritual that has been brought forward over the centuries into the present. Again and again we find that the cognitively impaired will respond to ritual — rosary, structured and memorized prayer, liturgy, communion bread and wine, sacred song — long after they no longer respond to other things. We need to trust that God will find avenues to offer God's presence to these wilderness wanderers, just as was done for Israel — and we need to be watchful for and facilitate these avenues as best we can.

Like the person with dementia and their caregivers, the Jewish exiles in Babylon were in an unknown land, surrounded by people alien to them, powerless, frightened, frustrated, angry and depressed. They longed for a time when they might see meaning in their existence and evidence of God's love for them. They asked, "How can we sing the songs of the Lord while in a foreign land?" (Psalm 137:4) and "...we are wasting away...How then can we live?" (Ezekiel 33:10). They lamented, "The Lord has forsaken me, the Lord has forgotten me." To which God responded with this tender message: "Can a mother forget the baby at her breast and have no compassion on the child she has borne? Though she may forget, I will not forget you! See, I have engraved you on the palms of my hands" (Isaiah 49:14-15).

Waiting is also a theme throughout scripture with relevance for people with dementia, their caregivers and pastoral care providers like us. Noah waited for the floodwaters to dissipate; Sarah and Abraham waited for a child; Jacob waited and worked fourteen years for Rachel. God answered each of them in

due time and said to Israel, to us, and to those persons and families struggling with dementia, “Those who wait upon the Lord shall renew their strength, they shall mount up on wings as eagles” (Isaiah 40:31)!

Some of you who read this article will do so after already having walked with dementia sufferers and their families for many years — in a personal capacity, a professional capacity, or both. Others will be just beginning their journey. Regardless of where you are, it is my hope that some of the insights and reframing offered in this article will prove to be both personally uplifting and practically useful. More importantly, I hope they will stimulate further exploration and creative thought about how to most effectively engage the “dementia dilemma” from theological, spiritual, and pastoral care perspectives.

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Gary Sartain is an ACPE Supervisor and Board Certified Chaplain with the Association for Professional Chaplains. He is currently called by the ELCA to serve as Director for the North Central Region of the Association for Clinical Pastoral Education, Inc., and does so from his home in Apple Valley, MN. From 1993 to 2003 he served as Associate Director of Spiritual Ministries and Director of Clinical Pastoral Education for the Evangelical Lutheran Good Samaritan Society. Ordained in 1972, he began his ministry as an assistant pastor in northern Minnesota and then spent 20 years in Canada, where he served as a clergyman/pilot for the Evangelical Lutheran Church in Canada in the Canadian arctic and then later as Director of Ministry and Flight Operations for the Lutheran Association of Missionaries and Pilots. From 1987 until returning to the United States to join the Good Samaritan Society in 1993 he served as a hospital chaplain and then Regional Coordinator of Chaplaincy Services for the Province of Ontario. It was during this time that he became certified both as a chaplain and as a clinical pastoral educator.

Fading

Pieces and parts began to unravel, slowly at first, like snags in a sweater, later catching on unseen protrusions creating bigger holes.

One evening I received a phone call from my mother. My father had been losing his sight to macular degeneration for several years, and one day it seemed like that dimming sight had all but disappeared. It was as if a light switch had been turned off. This happened on a day in February of this year, a little over a month before he died. I had been struggling with how to frame his memory and vision loss in words. Hearing the conversation my parents had during that morning in February, condensed here, was the trigger I needed to start writing.

“I’m missing something.”

“What are you missing?”

“I don’t know. I’ve lost something.”

“What is it?”

Pause

“I can’t see you.”

My dad has been fading for a while. His vibrant reds and blues and deep browns have become paler; water color washes, sepia tones, parts erased away, some smudged, nothing left is crisp or clear, growing fainter into a world where words disappear and visible light is lost as quickly as a balloon loosed from its string.

My father has been many things: a cleaner of inner-city chicken coops, an army clerk in the tropics of the Philippines, a little boy at Burroughs Elementary, a player of ragtime piano, a seller of hymnals and choral music, a quiet presence in the world around him. Like so many fathers, he taught me to waltz while I stood on his feet. He encouraged and supported without pushing. He read books and traveled. He showed me that what you do to make money is not who you are, that work can allow you to do what you love even if what you love doesn’t make you a cent.

At first the lapses were small; little things easily remembered by keeping a list. Sight diminished, driving ceased. Pieces and parts began to unravel, slowly at first, like snags in a sweater, later catching on unseen protrusions creating bigger holes. Solo trips to the Y became un-navigable. Days of playing music for the “old folks” diminished along with the ability to see the music, recall the whole tune. A health incident stripped away more, shifting abilities, decreasing the radius of daily activity. Language to describe what was happening sometimes went astray.

“Will Grandpa still be able to play the piano?” A question asked by a little girl – the youngest of the



grandchildren. To her, the core of Grandpa is music from his fingertips; music providing glimpses of the vibrant colors from his earlier years. A trip to the piano made several times for the same tune, not remembering that it was just played, not realizing that only a portion is kept in muscle memory, but enough. Enough for a little girl, enough for the man. More will fade. The warm sepias may slowly be replaced by colorless grays. The body will remain as a placeholder, a connection to the soul inside, until even that physical presence disappears.

“I’ve lost something.”

“What is it?”

“I can’t see you.”

“But I am here. I am in your heart.”

Anna Bliss lives in South Minneapolis with her husband and daughter (the little girl who asked the question about Grandpa and the piano). She works on web sites by vocation and writes by avocation. Previous work has been published in the Minnesota Women’s Press and on the Trial Balloon blog on the Minnesota Public Radio web site.

Search for the Memory of God: Pastoral Care with the Cognitively Disabled

Not even a brain injury or dementia which often accompanies old age can strip away one's spiritual self.

Preface:

This paper, *Search for the Memory of God*, was written in 1994 while working on my Doctor of Ministry program, and became a sub-theme of my dissertation entitled, *Wholistic Health Care in the Nursing Home Setting: The Chaplain and the Interdisciplinary Team*, 1999 (available at Luther Seminary Library, St Paul, MN). The field of study for this degree was Aging and Health. To this end I completed a two-year certificate program at Luther Seminary with the *Center for Aging, Religion and Spirituality* (CARS), Dr. Melvin Kimble, Director. The people I have been called to serve have profoundly shaped my chaplaincy ministry. Some of their stories are told in this paper.

Abstract:

In this paper I begin to ask the question, "Where is the memory of God stored, kept safe, or as stated in the Lutheran Baptismal liturgy, 'sealed' for those who have lost their ability to remember?" One of the most profound ways in which one's spiritual core self makes connection with the outside world is through opportunities to participate in familiar religious rituals. Religious rituals themselves vary according to one's faith traditions; however, rituals often function to improve the state of well being for those people who suffer from brain damage or dementia, and their families. The case studies discussed in this paper show the value of ritual to trigger a memory of God in these cognitively impaired people, and the importance for their pastoral care givers to use ritual as a basis for pastoral ministry.

"Where is the memory of God stored, kept safe or 'sealed' in one who has lost his/her ability to remember because of cerebral trauma, illness or disease?" I first began to wrestle with this question in 1981, while serving my seminary internship at a state hospital for patients with brain disorders and mental retardation.

His name was Pete. He was a 6'2" gentleman in his fifties who suffered severe brain damage as the result of an auto accident when he was in his 30s. His brain injury left him unable to speak, disoriented to person, time and place, totally dependent on others to care for him. His normal behavior was to stand, lie down or at times sit in a catatonic state. His arms were stiff and stretched out in front of him



or at his sides. His knees barely bent when he sat on a chair. Pete stared straight ahead with no expression on his face. He did, however, chew and swallow when fed.

Before his accident Pete was an active, every Sunday churchgoer from childhood, attending Sunday School, Bible camp and confirmation. As an adult Pete taught Sunday School, sang in the choir

"Where is the memory of God stored, kept safe or 'sealed' in one who has lost his/her ability to remember because of cerebral trauma, illness or disease?"

and served on the church council. Pete's plan of care at the hospital reflected his religious background stating that Pete should be brought to all Protestant church services and related activities.

I met Pete at one of these activities, a song service

led by the chaplain. About twenty people were seated in a circle on folding chairs in the chapel. A guitarist sat on a stool in the center of the circle playing some old Gospel-type hymns and church camp songs. My role was to sing the words to the songs while I walked slowly around the inside of the circle facing the residents, making eye contact whenever possible, extending my hand as an invitation to shake hands, trying to involve the residents in some way. Some residents knew the words and could join in singing. Others, like Pete, sat stone-faced as though unaware of what was going on. It was noted in Pete's medical chart that nursing attendants were almost always successful getting Pete to "sit" when they brought him into the chapel, whereas, he would refuse to sit in the game room.

As I walked around the circle singing, "Children of the Heavenly Father," I extended my hand toward Pete. Nothing, no response. I reached up and rested my hand on his stiff, hard shoulder, singing and gently rubbing the knotted tissue between his shoulder blades. When the song was finished I went on to the next person, a Down's Syndrome young man who wanted a hug. About fifteen minutes later when I had come full circle and was again standing in front of Pete singing our regular closing song, "Friends," I noticed Pete lifting his stiff right arm from side to side. He continued the movement attempting to take my hand. I grasped onto his fingers while he moved my hand toward his shoulder. In doing so I felt a warm tear on the back of my hand as it brushed up against his cheek. With my hand once again on his shoulder, his stiff arm returned to his side. Pete's stony countenance did not change, that is, except for a couple of tears which glistened on his cheeks.

In her book, *Ritual and Pastoral Care*, Elaine Ramshaw advocates for bringing those who are retarded and brain injured as well as all cognitively impaired persons into the worship community. One never knows what will trigger their memory of God at any given moment. It may be symbols of water, bread, wine, oil, light or a human touch. "Persons who are senile or brain-injured have disturbances of thinking.... The familiarity of ritual may offset even severe impairments of memory. I have heard again and again from pastors that a ritual order will trigger a familiar, life long memory pattern even in senile people who are not tracking at all well in the present." (1)

Each week for the remaining two months of my internship at the state hospital I paid special attention to Pete every time he attended the "Song Service" or worship. However, while I was there he never again exhibited any response.

I shared this incident with the hospital interdisciplinary team at Pete's next care conference. No one had any explanation for this one-time breakthrough into Pete's inner self. Yet it happened. And I am still remembering it after thirteen years. Subsequently, my ordained ministry led me into specialized ministry where I have continued to encounter people

like Pete who seem to have lost their memory of God. Or have they?

In his book, *The Unconscious God*, Viktor Frankl writes:

We must not neglect the fact that being human is always individualized being. As such, it is always centered around a core, and at this core is the person, who, in the words of Max Scheler, is not only the agent but also the "center" of spiritual activity. I would say that this spiritual personal center is encompassed by the peripheral psychophysical

In spite of the damage to Pete's brain that destroyed many of his abilities, deep within him was his self, which was still intact, and for a moment a spiritual connection was made.

layers.... To sum up, spiritual phenomena may be unconscious or conscious; the spiritual basis of human existence, however, is ultimately unconscious. Thus the center of the human person in his/her very depth is unconscious. In its origin, the human spirit is unconscious spirit. (2)

In a taped interview with Dr. Melvin Kimble, Frankl expanded on his idea, applying it specifically to persons with dementia. He stated, "At the innermost core of the human being, after all is taken away by disease or anything else, is the self. One cannot be impaired at the inner most core of the human person. Nothing is irrevocably lost in the person with dementia; it is there, but unable to access the memory. Beyond verbal expression there may be a look, a smile, or a tear signaling that the person is communicating with you from the inner most core of who he/she is." (3)

One can only speculate what it was that triggered a physical and emotional response from Pete that one day. Was it the ritual chapel setting? A familiar hymn? The gentle yet soothing touch? The regular closing song? God only knows. One possible explanation is Frankl's idea that at the core of Pete is self, which is spiritual. In spite of the damage to Pete's brain that destroyed many of his abilities, deep within him was his self, which was still intact, and for a moment a spiritual connection was made. It may have been this, along with the familiar ritual, setting and sounds, which caused Pete to act.

During the years since that day with Pete, while serving as chaplain in long-term care facilities, I have witnessed many more special "spiritual moments" with those who are cognitively impaired, each one as unique as the person involved. Another example is Anna's story.

Anna was baptized, educated, confirmed and mar-

ried in her rural Lutheran Church. She remained actively involved in the church until age 82 when she suffered a severe stroke followed by several smaller strokes which affected her speech and left her paralyzed. The last 12 years of Anna's life were spent in a nursing home. In the final months of her life, Anna did not speak or exhibit any recognition of her five children and their families, who continued to visit regularly. When the end appeared to be near, Anna's family stayed around the clock in shifts. Five days passed and Anna still clung to life. On the sixth day all of Anna's family gathered. They requested a prayer service including Holy Communion to be held in Anna's room. After the Meal, I prayed the prayer of Commendation giving Anna to the care and presence of her Savior, Jesus Christ.

We were all standing there quietly after the prayers, watching Anna continue to struggle for each breath. Suddenly, she gasped and opened her eyes, which had been closed for weeks. She seemed to look around the room and then to the window at the foot of her bed. Her normally brown eyes seemed to be all white and shiny. They were fixed on the window, where a cross hung. She spoke clearly so we all understood, saying, "Do you see Jesus?" Needless to say we were all in shock. She then turned her eyes and looked at her daughter who had been her primary care giver. Anna said her name. She then looked at each of her other four children and said their names. Her eyes returned to the cross on the window. She said nothing, took a deep breath and died, after which her eyes became brown again.

Some moments are so spiritual they must be left in the realm of mystery. Anna's family looked to me for answers. I shook my head and said I had none. I joined the family, seeking comfort in the fact that there were twelve of us in that room with Anna, and we all saw and heard the same things.

I turned to Ramshaw in search of some answers. In her chapter on "Ritual with the Dying" Ramshaw states:

There may be significant possibilities for ritual care near the time of death. If the dying person is unconscious, the commendation may be prayer for the sake of the family and friends gathered around, as their way of saying goodbye. Besides, people have been known to remember things said while they were unconscious; thus the dying person may be more "present" in the ritual than you think.... A number of people writing about the process of dying have observed that sometimes the patient comes to terms with the fact that she is dying before the family does. Sometimes, she finds it difficult to "let go" because she senses that her family is not ready to let go. In such cases, the use of a rite of commendation with the family may be a way of the family giving her permission to die. (4)

In a follow up visit with Anna's family after the

funeral, I shared some of these thoughts from Ramshaw. I assured them it is not uncommon for religious people with cognitive loss to experience significant spiritual connections shortly before death.

Alice's story is another example. She was born in Oslo, Norway, in the early 1900s. Before she was one month old her parents brought her to church to receive the Sacrament of Holy Baptism. When she and her family moved to the U.S., their church was the center of family and community activities. Alice served on her church Altar Guild for forty years, until symptoms of dementia made it impossible to

It is not uncommon for religious people with cognitive loss to experience significant spiritual connections shortly before death.

continue. Eight years ago Alice's condition was diagnosed as probable Alzheimer's, requiring skilled nursing, and she was admitted to long-term care.

Alice now sits in her wheelchair uttering nonsensical partial sentences in a mixture of Norwegian and English. She is, at times, physically abusive to her caregivers and shouts rude, sometimes obscene words at black male nursing attendants. She can be disruptive in activity programs, and many times needs to be removed for the sake of others.

In worship, however, Alice is consistently calm, reverent and appropriate. When she is offered the bread and wine she opens her hands to receive, then says, "Takk." When the chaplain offers her the "Peace of the Lord," she extends her hand and sometimes says "Yup" or "Takk." Her serenity lasts only until she gets to the elevator and then she reverts back to her non-chapel behavior.

Often chaplains in long term care experience people like Alice. People with various kinds of dementia often respond appropriately to religious rituals. I have heard residents who have forgotten their own name recite the entire Apostles' Creed, Lord's Prayer, and Rosary. In one case recently, a resident who had been non-verbal for over a year sang every word of the hymn, "Blessed Assurance," a few hours before she died.

I wish all who suffer cognitive loss could experience these precious moments of spiritual connection, both for the sake of those who seem to have lost their memory of God, as well as for their families. Sadly, however, for some there may be no obvious indication of a spiritual connection.

Pastor Joe, like others I've cited, also was a dedicated man of God. He was a professor of Biblical studies at a church college for years. In a visit with

his wife, I learned how Joe had wept when he began to realize he could no longer even remember the words of the Lord's Prayer. Later, as his disease progressed, there were no apparent signs of spiritual connection when his wife took him to worship services. "This is the saddest of all consequences of this disease," she told me.

In his book, *My Journey into Alzheimer's*, Robert Davis tells his own story:

The sunlight of Christ had always filled and thrilled my soul in those drifting moments before sleep carried me away. Now I discovered the cruelest blow of all. This personal and tender relationship that I had with the Lord was no longer there. This time of love and worship was removed. There were no longer any feelings of peace and joy...what was in my mind? Blackness and darkness of the worst kind. As soon as I let go of my concentration to try to fall asleep, there was nothing. This vacuum was filled with terrifying blackness. Sometimes Betty would hear me crying or even screaming in my sleep. She would hold me, speak soft words of reassurance to gently bring me back to reality. (5)

Davis' wife, Betty, assisted him in writing his story and then wrote the final section herself. Her story is echoed over and over again by those who love and care for those with Alzheimer's.

Speaking at a seminar sponsored by Lutheran Long Term Care Conference, Elaine Ramshaw shared her insights into the mysterious realm of religious rituals and their capacity to imprint memory on the mind, heart and soul. She stated from her book,

It is true that there is a functional hierarchy in the act of blessing, as in all ritual, and all ordered human interaction, for that matter. Ritual authority in a Christian context, however, is invested primarily in the words and actions because they derive from the invitation of God, and only derivatively in the person of the ritualizer, as a means to the end of extending God's invitation reliably. What needs to be renewed is the confidence in God's intention to come to us through human symbols of word and gesture. When God's invitation is understood as the basis of ritual authority, it is possible to avoid both the arrogance of ministers who like to be above the crowd and the wishy-washy delivery of those who are authority-shy. A lively sense of grace will put the authority where it belongs and produce some surprises. (6)

Ramshaw speaks a fresh and freeing word of grace to chaplains serving congregations of people with dementia and other cognitive impairments. When one of these dear ones experiences a spiritual connection deep at the core of self, it is cause for celebration. When this lively sense of grace is unleashed, God produces some wonderful surprises. Stories like the ones told by Robert Davis and Joe's

wife are heartbreaking. However they would be the first to say, faith endures.

In the baptismal liturgy of my Lutheran tradition, the pastor says to the one receiving the Sacrament, "Child of God, you have been sealed by the Holy Spirit and marked with the cross of Christ forever." (7) This is the Word of the Lord for all God's people, and it is unconditional. In Ramshaw's section on the Sacrament of Baptism, she argues for the appropriateness of placing the Baptismal font at the entrance of the worship space, so that it is awkwardly in the way and people must walk by or around it

I would also advocate for the presence of a Baptismal font in the chapels of nursing homes affiliated with sacramental denominations, in order that those residents who suffer cognitive loss may also be visually stimulated and remember their baptism.

in order to get to their seat. In this way we are reminded how each of us entered God's community, by way of the waters of Baptism. Further, I would also advocate for the presence of a Baptismal font in the chapels of nursing homes affiliated with sacramental denominations, in order that those residents who suffer cognitive loss may also be visually stimulated and remember their baptism.

In the introduction to his book, *Sacramental Pastoral Care*, Robert Kinast argues for the prominence of Sacraments in pastoral care settings. He quotes William Willimon: "Worship is a major, if recently neglected, aspect of pastoral care. Worship can be enriched by a better awareness of the pastoral dimensions of so-called priestly acts. In turn, pastoral care can be enriched by more attention to the priestly dimension of so-called pastoral functions." (8) Willimon uses worship, understood as the public rituals of the congregation, as his starting point in identifying opportunities for pastoral care.

When care-planning for people who are institutionalized in care centers, especially those suffering from various types of cognitive loss, it is important to get a detailed social history which includes the patient's religious history, in order to identify opportunities to use religious rituals as an appropriate means of therapeutic pastoral care. In many cases, by the time cognitively impaired patients are admitted to a long term care facility, they are no longer able to provide that type of information themselves. Chaplains, as members of the interdisciplinary team, can most often get a religious history from a family

member by phone or at the initial care conference. In this way, worship attendance, when appropriate, can be a central part of a resident's whole plan of care. In addition, other disciplines may take into account attendance at worship as a priority, and schedule other daily cares and activities around the worship hour.

In addition to attendance at worship, other sacramental rituals may also be helpful, even therapeutic for cognitively impaired nursing home residents. Examples include in-room Holy Communion, services of anointing, Rosary, Scripture reading and prayer, depending on denomination practices.

Elderly Roman Catholic residents continue to request — even insist on — the “Last Rites” when they are near death, even though the Church now refers to this Sacrament as the “Sacrament of the Anointing of the Sick.” A problem arises when a priest is unavailable, due to shortage of clergy. Kinast addresses this issue:

Anointing is meant for the living; it assumes that a seriously ill person is not about to die but does need special support in order to endure the illness with a Christian spirit. Moreover, serious illness pertains not only to physical but also to psychological and emotional disorders. Thus, a wide range of circumstances can call for anointing. Similarly, communal anointing services in parishes and health care facilities are broadening the Church's experience of anointing...” great care and concern should be taken to see that those of the faithful whose health is seriously impaired by sickness or old age should receive this sacrament” (No.8)...far from restricting the sacrament as in the past, the revised Rite urges its frequent and widespread use. (9)

Older Roman Catholic residents are accustomed to the former teaching of the Church and consequently place great importance on the priest's blessing at or shortly before death. Often this blessing provides the permission needed to die. Devout Roman Catholic family members also experience a sense of closure and are more ready to let go of the one they love.

The question, “Where is the memory of God stored or kept safe in those who suffer cognitive loss and can no longer remember?” is a subject of ongoing study, research, and contemplation. Those who have spent their lives studying aspects of the unconscious, like Frankl, help us to understand how uniquely human beings are created. One's spirituality is safely positioned at the core of one's being. Not even a brain injury or dementia which often accompanies old age can strip away one's spiritual self. In the end, faith assures us that God will preserve and protect that which is Holy in all the people of God.

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The Rev. Donna Erickson, D. Min., APC — Board Certified Chaplain, retired September 2007, after more than twenty-five years in specialized ministry, and is now living in Houston, Texas. She was the former Director of Spiritual Health Services for Ebenezer Ridges Campus, Burnsville, Minnesota. She served as CPE Clinical Coordinator and On Call Chaplain at Fairview Ridges Hospital, Burnsville, MN. She also served as Chaplain at Ebenezer Hall, Minneapolis, MN, and Director of Spiritual Care at Margaret Parmly Care Center, Chisago City, MN. Pastor Erickson was Pastor-Developer and Pastor with her husband of St Mary Magdalene Lutheran Church, Savage, MN, and served Zion Evangelical Lutheran Church, Chisago City, MN, as Associate Pastor.

Notes in the Red Silk Notebook: Living with Dementia

This morning as we worshipped in the Nursing Home Chapel, I realized how much we need the support of others.

I share these excerpts from the journal I kept during the first year of my husband's slide into dementia, in the hope that those who minister to others in similar circumstances will have a deeper understanding of the changes that dementia brings to an intimate relationship, and what it is like for one caregiver as she attempts to come to terms with these changes.

Sometime during 1986 my husband K. showed occasional signs of forgetfulness and confusion in the simple chores of daily living. We consulted doctors in a variety of disciplines, including psychiatry and neurology. Early in 1987 he spent a month in a mental hospital, where he underwent a wide variety of tests in order to learn the reasons for his mental confusion. The results of the tests showed a progressive dementia, but the doctors could not agree on a final diagnosis. Some thought it was the result of Transient Ischemic Attacks, or *TIA's* — multiple tiny strokes in the brain. Other doctors said that it was the result of depression, or the combination of drugs he was taking for various physical illnesses. Still others thought he had Alzheimer's disease. When he returned home from the month's stay in the hospital, I arranged for day care so that I could continue to work. Caring for him became more and more demanding. In the summer of 1987 I went to visit family to rest and recover my strength.

August 1987

Midway through my vacation in Wichita I bought this diary at the museum. It was sitting there on the shelf in the gift shop. I was attracted to its lovely red silk cover with a Japanese design, and as I picked it up I liked the feel of the leather binding in my hand. I thought I would write about where I am today.

K. is in Residential Respite Care. He is there because I need a rest. I miss him terribly. I miss who he was — but I have found some of who I am, and that is very important. It's raining here in Kansas, a most unusual time for rain. I feel the pain and wonder — What's next?

January 1988

What's next? I asked. Had I known, would I have come back from Kansas? What's next was watching K. regress. What's next was seeing K. crawling on all fours, unable to feed himself.

What's next was making desperate calls to nursing homes, and finally finding a place for him in a



nursing home on the Jersey Shore. It's not the best, but he is safe.

March 1988

Breathing a sign of relief only to have it stopped in mid-breath — he is not safe. A call from the nursing home sends me racing down the Parkway. He has been moved to the local hospital. I find him tied to a bed, ranting under his breath, neglected, feverish, thin as a rail. I speak to his doctor who tells me of some changes she made in his medications. I stare at

K. is in Residential Respite Care. He is there because I need a rest. I miss him terribly. I miss who he was — but I have found some of who I am, and that is very important.

her hands; her dark red nail polish is chipped. If she can't care for herself, I think, how can she care for him?

I spend the night in the Emergency Room, watching him fade; my dear friend P. supports me. "He's dying," she says. She's a nurse, I am sure she is right.

I make more calls — this time to get an ambulance to transport him to another hospital.

Finally, he is admitted to the quiet efficiency of a well-run ICU in a different hospital. He is there for almost three weeks while they straighten out his meds and help him to recover his strength.

April 1988

Why am I crying? I feel the sadness, the exhausting desperateness of the situation, and I wonder why he lived. What meaning is there to all of this? After weeks in Intensive Care, he is ready to return to the nursing home, but I can't imagine taking him back to that place.

A group of colleagues are gathered in my living room for a meeting. It is noon and the phone rings. It is a Lutheran Nursing Home in southern New Jersey. They have a room for him.

I feel like God has reached down from heaven and picked me up in God's hands. With the care of the staff of the Lutheran Home, K. starts to progress physically. I plan to bring him home this weekend to celebrate his birthday.

May 1988

I have been working with a patient who is schizophrenic, and, while writing a report about her thought disorder, I begin to make connections with similar disordered talk from my husband. Reality checking with Pastor helps me to gradually straighten out my own thoughts. I trust my inner voices more because of this. I am not afraid to hear others judge K.'s actions as strange or bizarre. Understanding thought disorder more fully puts more pieces in the puzzle.

Last night when I talked to K. and he was jumping from one subject to another, I didn't translate his questions into "What's wrong with ME?" It is his neediness coming out. Understanding this does not take away my need for healthy dialogue, but I see how K. controls his world. He tries to manage his dependency by attempting to control me.

July 1988

Yesterday I sat and talked with the Social Worker at the Lutheran Home. She affirmed my perception of what has been going on with K. What she said was, "He is a geriatric with some brain damage, possibly from drugs and anesthesia. He's had a psychotic break and now is unable to function autonomously. He attempts to control his anxiety by manipulating others to make his environment predictable and secure." She does not think he has Alzheimer's; neither do I. "He is regressed, childish and demanding," she says. "Eventually he will become 'institutionalized' and be more content here." These last words make me very sad, but a part of me realizes that if he feels "at home" it will be easier on both of us.

I see so much of what she described when I tell

him he cannot come home this weekend. He tries to play on my sympathy by saying he misses our dog, but when I offer to bring Butch down with me K. says he thinks it will be too much trouble. It is the kind of switch he does that I often miss, but is "crazy-making" to me.

"Eventually he will become 'institutionalized' and be more content here." These last words make me very sad, but a part of me realizes that if he feels "at home" it will be easier on both of us.

I need to write this and read it often so that I will not backtrack. I found myself so depressed early this week that I couldn't eat or sleep. I realized that I've not come as far as I'd like to think I have. This could go on for a long time, and I must make a new life for myself. I can only pray for God's mercy on us.

August 1988

Today I feel again the truth of the Social Worker's description of K. You might say I saw him through her eyes. He lacks ego functioning, and when I hold my boundaries he gradually deteriorates — not severely — but it is unquestionably there. Moments of clarity alternate with confusion. Recent memories of places we visited are balanced against his inability to figure out how I will get home from the Nursing Home. In his mind we are so merged that if he is limited then so am I. He has decided that Medicaid limits my visits. I let that stand.

This morning as we worshipped in the Nursing Home Chapel, I realized how much we need the support of others. It is a difficult shift for both of us. We are two people who thought that as long as we had each other, all else would be well. Now we rely on those who serve God through caring for people like us.

K remained in the Lutheran Nursing Home where his mental and physical state continued to gradually deteriorate. We continued to seek for an answer to his condition and I continued to write in my journal about our visits. On December 31, 1989, I received a call informing me that he had pneumonia and was being moved to a hospital. On my last visit with him, he seemed clearer than he had been in a long while. He recognized me, and when I asked him if he would like to go home, he smiled and said, "Of course." He died on January 9, 1990.

I am eternally grateful to the staff at the Lutheran Home for the loving care that they gave to K. and the support that I received from them. I also thank my colleagues and students in the CPE groups with which I was associated, and most of all the pastors and members of St. John's Lutheran Church in Summit, NJ for their support.

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Engaging the Spirit of Persons with a Dementia

Spirituality is *lived belief*, not just cognitive belief.

The word “dementia” is like the word “cancer,” a ‘catch-all’ word that describes a general set of common symptoms, but has several distinct geneses. Alzheimer’s disease is the most common form of dementia, but there are other forms (see figure 1) that have many of the same symptoms: a decline in cognitive function that will ultimately lead to death, unless the person dies of some co-morbid malady. Alzheimer’s disease (AD) is characterized by a slow steady decline that can be evident in a patient’s behavior 20 years before diagnosis. Thus the total time between the beginnings of AD and death can be as long as 30 years. Therefore, chaplains need to be aware of the possibility of a patient having a dementia, and thus altering behavior and cognitive capability for many years before a physician is able to make a diagnosis (Alzheimer’s Association: www.alz.org).

Many people are afraid of dementia. In fact I wonder if more people are afraid of the “D” word (Dementia) than they are the “C” word (Cancer), since so many people living today are cancer survivors. In addition, people are often afraid of “losing their mind,” or “becoming less than the human being they currently are.” In today’s hyper-cognitive world, the loss of cognitive abilities due to brain injury, dementia, or even mental illness is immediately met with stigma and fear. I have observed that the frequency of visitation of family members, even clergy, declines as the dementia progresses. Family members mourn the loss of a loved one who still breathes while, I believe, clergy are put off by the inability of the patient to respond to the many words, concepts and abstractions that form the basis of most theologies. The philosopher, Descartes, seeking to determine if he actually existed or if existence were but a dream, postulated: “I think, therefore I am.” Well, what happens when a person can no longer think, at least in what is deemed normal thinking? What happens when a person loses even awareness of their own being and distinctiveness from others? Does that person become less than human? Many family members describe dementia as “the long good-bye” or the “never-ending funeral” as their loved one’s cognitive self literally disintegrates before their eyes.

What does it take for a person to be declared human? A person is human at conception, pro-life advocates would say. A person is human at birth, others would suggest. When I was in seminary (years and years ago) it was suggested that being “created in the image of God” did not suggest physical appearance but rational thought. What separated the human from other mammals was an ability to



think and reason. But what if being “created in the image of God” means that a person reflects the reality of God like a mirror reflects the image of that which is before it? (Sapp, Stephen “Hope: The Community Looks Forward,” in Donald K. McKim, editor, *God Never Forgets: Faith, Hope and*

Figure 1

Mild Cognitive Impairment (MCI)

Vascular Dementia
Mixed Dementia
Dementia with Lewy Bodies
Parkinson's Disease
Frontotemporal Dementia
Creutzfeldt-Jakob Disease (CJD)
Normal Pressure Hydrocephalus
Huntington's Disease
Wernicke-Korsakoff Syndrome

Alzheimer's Disease, Louisville, Westminster John Knox Press, 1997, pp. 90-96.) What if a person’s ultimate humanity is based on spiritual principles rather than those of physiology, psychology or sociology? What if the essential nature of the human is spiritual...that we are spiritual beings having a cognitive experience rather than cognitive beings having a spiritual experience?

In an interview following his keynote address to the Annual Conference of the American Society on Aging in 1991, Viktor Frankl described the human spirit as being ‘unassailable.’ Referring to the Biblical Book of Job he noted that the devil suggested to God that Job was faithful to God because Job was rich and had a great life. God then retorted that the devil could take away anything that Job had but not what Job is. “I may have a high IQ,” said Dr. Frankl. “I may have an ability to think, or write. All of these mechanical abilities might be taken away by disease, by Alzheimer’s, or by Mephistopheles. But the inner core of the person, their inner humanness is unassailable. Everything else can be taken away. But their inner spirit, their inner core, their ‘geistig’ [German word for human spirituality] cannot be taken away. Even with the most stricken patients this core can be seen: in a look, a smile, a tear running down their face” (see VHS “A Conversation with Dr. Frankl” www.terranova.com). What is unassailable is a human being’s spirituality.

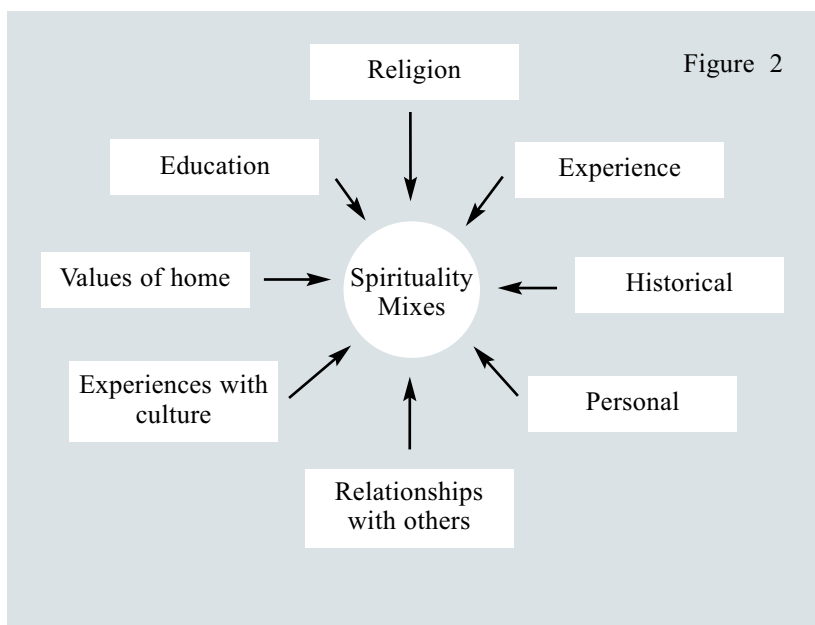
Spirituality can and does include a person’s religious beliefs, but is also more than religious beliefs. For those who are or have been a part of a religious tradition, the beliefs of that tradition form at least a backdrop to their spiritual views. A person’s spirituality is what they believe, what they count on when the going in life is tough and no one is looking. A person’s spirituality can differ from their religious values. That is because a person’s spirituality is an amalgam of many, perhaps all of the experiences of life (see Figure 2).

People’s spirituality, their ‘tire-meeting-the-road’ belief, is shaped by the values of their family of origin, their education, historical events (such as 9-11, and/or living in WW II and/or experiencing life during the Civil Rights Movement and Viet Nam). Their spirituality, how they view their world, what they expect of God, self, and others has also been formed by experiences with culture, (being gay) their relationships with others (living in poverty), or their personal thoughts and beliefs that affect behavior and viewpoint from the inside-out. A person’s spirit, his/her geistig (Frankl), is the core of the person, influencing every behavior, value, belief, emotion that a person has.

Spirituality not only influences one’s view of God.

People’s spirituality influences every aspect of life (see Figure 3). It influences their view of suffering (is suffering merely suffering or can suffering have meaning?), compliance (do I trust that the medical professionals are trustworthy and can help me?), their expectations of God (how they pray and for what they pray), their openness to change (whether the future is open and, although scary, filled with opportunity — or is the future closed and life as I know it threatened by change?). A person’s core affects the ability to find meaning even in seemingly meaningless situ-

ations (whether I have the power to love others and, just as important, to be loved by them), even on what or whom a person can trust. As the Christian theologian and Existentialist Paul Tillich noted: “A person’s God is their ultimate concern” (Tillich, Paul, *Systematic Theology, Volume One*, page 14). Spirituality is *lived belief*, not just cognitive belief.



People’s spirituality, then, is their human essence, and thus can never be eradicated (Frankl). Certainly the way that they express and grow spiritually will change. Gone may be certain rituals, certainly their ability to cognate about those rituals. But they can still experience those rituals, know them for what they have meant (and still mean?) in their lives. Holy Communion, anointing of the sick, the singing of familiar hymns, the Our Father (Lord’s Prayer), or the Rosary, can still hold meaning even if that meaning cannot be described verbally or analyzed mentally. When asked, “If I am stricken with a dementia, can I have the same relationship with God as I have now?” the German theologian Jurgen Moltmann replied, “You may not be able to, but God can still be in relationship with you. It’s not just your relationship with God but also God’s relationship with you, and that’s the important one” (Sapp, Stephen, in a presentation at the 1998 Annual Conference of the American Society on Aging).

To connect with the spirit of a person stricken with a dementia, the chaplain needs to be aware, observant, flexible, and connected to the spiritual-in-life enough to see the spirit in another and return what might seem to be mere embers into the flame that did (and does?) lighten the soul. Nursing has given us a simple format to use (Highfield and Cason, 1983 “Spiritual Needs of Patients: Are They Recognized” in *Cancer Nursing* p. 188). The authors suggest that there are four Spiritual Needs of

the Human Person (see Figure 4). Note that this list is not only designed for healthy persons, or even cognitively aware persons. It defines the spiritual needs of the human person...all persons. These spiritual needs are: the need for meaning and purpose in life, the need to give love, the need to receive love, and the need for forgiveness, hope and creativity. A few comments on each of them would be helpful.

The Need for Meaning and Purpose in Life

Viktor Frankl quoted the philosopher Martin Heidegger, who said, "If I have a reason to live I can survive any how I have to live." For Frankl, as in most religious traditions, the search for and the discovery of meaning is paramount to the human condition. In fact, most, if not all, faith traditions provide answers to the big questions in life, injecting meaning and purpose in life. How does a person with advanced dementia find meaning? Some anecdotal answers:

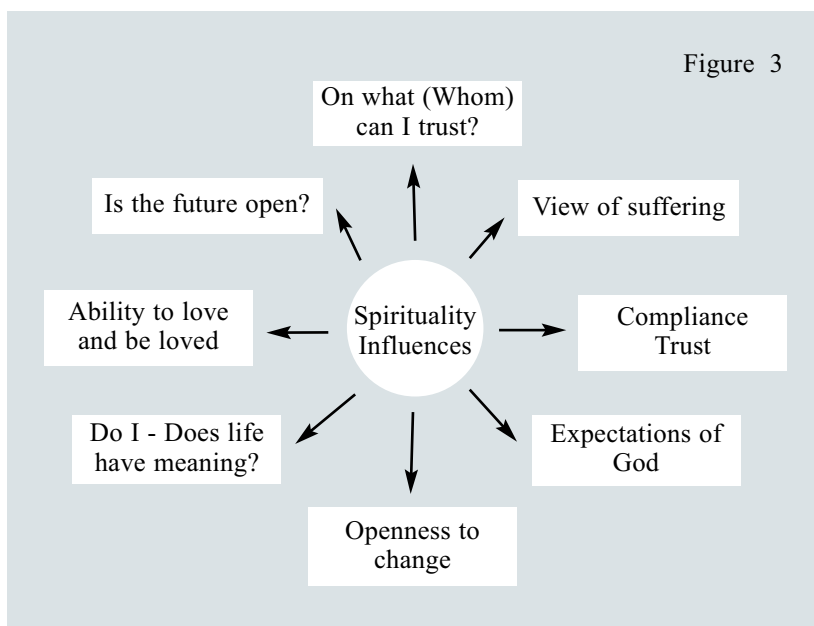
- A member with a moderate-advanced dementia was lector the Sunday I attended. A friend stood with her showing her where to begin and when to stop reading.
- A resident was given the 'job' of folding a few towels and wash clothes. Staff profusely thanked the resident for her wonderful work, went into the 'chart room' at the nurses' station, mixed up the freshly folded towels and returned them to the resident saying "We found some more. Would you like to fold these as well?" With a big smile the resident happily set to work.
- Participants in adult day care were each given a 'buddy' and the task of sharing program events with their buddy.
- A residential memory-assist facility gave residents chores, such as feeding an animal (they had many), watering plants (the plants would die if overwatered) and straightening magazines in the common area.

The Need to Love

Every person has a spiritual need to get outside of his or her self and to love another, whether that 'other' is a plant or a person. The celebration of birthdays where the community gathers to honor someone other than self is vital. An opportunity to create works of art through paint and canvas, or modeling clay, builds the self as the self shares with others.

One retirement community hired a local artist to develop a resident-focused painting, using acrylics. The artist made sure that everyone painted at least a little, with the beliefs that 1) there are no mistakes in painting, only creative events; and 2) anyone who can scribble can paint (see www.lindabounds.com). The encouragement of friendships, conversation groups, sharing of memories of the past, can encourage a person to love, no matter what their cognitive ability might or might not be.

There are many communities that have a number of soft, cuddly, washable dolls throughout the facility. Many a resident will 'adopt' one of these dolls as their own, demonstrating a great deal of love for this inanimate object that, in their mind, has become as real as you or I.



Gardens can be a wonderful place to demonstrate love and care. Many gardens are raised to table height so that patients can easily access and care for the plants.

Providing old photos, simple games and sensory toys that encourage interaction between residents and visiting family members is very effective. Activities departments seldom use the resource of visitors to enhance their activities programs. Many visitors do not have a clue as to how to relate to a person with a dementia.

Following a visit from her husband where they played games and looked at old pictures, a resident asked a staff person, "Who was that person?" The staff person replied, "Who do you think he was?" "I don't know," the resident continued. "But he certainly was a very nice man."

The Need to Be Loved

Everyone has a spiritual need to be loved. But for some people, to allow another to truly love them feels frightening. And yet, there is the yearning to allow someone into our inner core and touch us where we really live. Persons with dementia have that same need.

Some ways that the need for love can be fulfilled with persons with dementia are:

- Staff and visitors understanding what it is like to have a dementia and thus speaking directly to them, in simple declarative sentences, in a soft voice and a gentle touch.

- A person can feel affirmed when they are encouraged to play a game that does not require a lot of cognition to play, and thus they can!
- Singing a verse of a familiar hymn such as “Amazing Grace” or “In the Garden” or “The Old Rugged Cross” can bring a person to life once again.
- Sharing of the sacraments, that are inherently very tangible (bread and wine) and yet are filled with meaning that is given them by the residents/patients/parishioners themselves, is fulfilling.
- Massaging hands with fragrant lotion can touch the soul as well as the body.

The Need for Forgiveness, Hope and Creativity

This need is not really three needs, but rather three ways to engage one central need: the need for an open future. This need is probably the most difficult of the four spiritual needs for a person with dementia to understand because it is more abstract. And yet the need is as concrete as the need to eat. Everyone has a need for their future to be open, filled with possibilities. Everyone needs to believe that the best days of their life are still to come rather than in the past. There is a need for a person to forgive (let go of) the past, to hope for the future (believe there is a light at the end of the tunnel even though the tunnel might at present seem very bleak), and to participate in the creation of that future. Some of the ways this spiritual need can be addressed are:

- Treating the person with dementia as an adult, with feelings, values, hopes and desires. The very climate of the environment can speak loudly to the fact that good days are yet to be.
- Avoiding feeling sorry for the person with dementia. Life with dementia *can* be good, particularly when people forget that they are forgetting. When I was chaplain in long-term care, I would save my visit to the memory assist area for late afternoon, when I was tired and perhaps a little depressed. The honest joy exhibited by persons who are living in the moment was contagious, challenging me to surrender the stresses of the day and the anticipation of the future.
- Giving a patient personal time and attention. Keep your comments short, declarative, and to the point. Allow time for the patient to process what you have said. It can take some time to find the right word in a brain filled with plaques and tangles. As Christine Dryden, a person with frontal lobe dementia said, “Don’t interrupt our thread of thought, but let us interrupt you when an idea comes into our heads, because if we wait, it will disappear. Give us time to speak...to find a word, and don’t feel embarrassed if we lose the thread of what we are trying to say” (Christine Bryden 2005 *Dancing with Dementia* p. 119).

- Of course, stay in the moment. Any question can be difficult for the patient to process. Remember, the person with dementia has no past or future, but they do have the present, possibly more fully than the chaplain!

Figure 4

The Four Spiritual Needs of the Human Person

1. The need for meaning and purpose in life
2. The need to give love (outside self)
3. The need to receive love (vulnerable)
4. The need for forgiveness, hope, and creativity (open future)

- Use objects to connect. Food (particularly appropriate ethnic food), photos, a painting hung on a wall, aromas can be wonderful starting points to engage a person with dementia. What about the old “what’s in the box” game? Cut a hole on the end of a shoebox large enough for a hand to pass through. Place an item into the box. Ask the resident to put their hand into the box and tell you what the object is without looking. You may have to demonstrate where to put your hand several times before a person with dementia will respond positively and even lose their fear of what is in the box.

- If the residents will allow you, gently touch them. Ask permission. Never touch people with dementia from behind. Look into their eyes and slowly, gently approach from the front. Body language will reveal whether or not they want to be touched.

The Chaplain’s Trump Card

Of the many gifts and strategies for engagement that the chaplain brings to people touched with a dementia is that they are comfortable with many religious traditions and many ways of engaging the Divine in life. Chaplains are not afraid of the “R” word (religion) and thus can use religion, when appropriate for the patients, very effectively. The advantages of using patients’ religious traditions to engage them are many:

- Music is stored in a different part of the brain, therefore allowing music to touch another when mere words do not.
- It is well known that long-term memory is the last to be invaded by dementia. Therefore singing songs of the person’s past can be very effective. In addition, songs that have been used at meaningful moments in the patient’s past last even longer in the memory-banks. “Amazing Grace” is one of the most memorable melodies of our culture. If the resident can’t sing words, why not just hum? “The Old Rugged Cross” is great for Protestants,

while saying the Rosary can be valuable for Catholic Christians.

- Remember rituals are good. Familiar words are good. Well-known songs are good. Memorable actions are good. Using too many words can be difficult.

- Worship and the actions that surround worship can be exceedingly helpful. Figure 5 provides a simple order of worship that has been found effective and helpful with persons who have dementia. Remember, memories are short, so the Order for Worship does not have to change much each week, if at all!

- Greet each worshipper personally and, if possible, by name both before and after worship. Make eye contact, smile and if appropriate, shake their hands.

- Make the Scripture reading, preferably a Bible story, brief.

- Use body movements and voice inflections to assist the reading.

- There is no need for a ‘sermon’ or teaching. Allow the Scriptures to speak for themselves.

- Consider using the old ‘flannel graph’ as a teaching aid. Nancy Gordon, Director of the CLH Center for Spirituality and Aging, has researched the use of wooden figures to tell stories like the “Good Shepherd” who goes out into the wilderness to find the one lost sheep (see www.spiritualityandaging.org).

- Sing only one verse of even the most familiar hymns.

- Use bulletins, especially ones that have religious pictures on them, even for the worshippers that do not read. When people go to church, they receive a bulletin. If the picture is engaging, residents will take it home and maybe look at it again.

- Read Scripture from a big Bible rather than from a printed page.

- Use any visual that you can. Bring altar furnishings and use a table in the unit or home to set up an altar. If possible, use candles.

- Have Holy Communion (Eucharist) as often as possible. Persons with dementia may not remember words, but they do remember receiving Communion (I can always tell when a person is Catholic. As I approach they stick out their tongues!).

- Do not place the wafer into the hands. Instead place it in the mouth. If you wish to offer both bread and wine, use intinction, where the server dips the bread into the wine.

- Be prepared for a person with a dementia to spit out the bread. Simply deposit it in a sandwich bag and appropriately dispose of it later.

Conclusion

Persons with a dementia. Many experience them as already dead, and though they do not want to admit it, feel as though the person is less-than-a-person, at least less-than-the-person-they-were. They are a challenge for cognitively intact persons to visit

Figure 4

Order for Worship

- One verse of favorite hymn
- The 23rd Psalm (King’s English)
- Scripture (one or two verses of events, not theology)
- Ask questions about Scripture seeking response:
What did it say? How do you feel?
- One verse of favorite hymn
- SHORT prayer
- Lord’s Prayer (traditional)
- One verse of favorite hymn

because they remove our comfort zones, demanding that we, as they, live in the present, not basking in past relationships or future hopes. Yet, as we have seen, looking at the person spiritually continues to affirm their essential personhood despite the decline in cognitive ability. As Virginia Bell and David Troxell note:

A Person with Dementia is....

- A person of infinite value
- A person with a name
- A person with a spirit
- A person with feelings
- A person with a will and a personality
- A person with a life story
- A person who has a physical environment
- A person who has the present moment.

A person with dementia may still be:

- A person who gives and receives **love** and affection
- A person who can **reminisce** and respond to stories from others
- A person who is **compassionate** and concerned
- A person who enjoys **verbal and non-verbal communication**
- A person who can be surprisingly **flexible**
- A person who has a **sense of humor**
- A person who is **productive**
- A person with intact **social graces**
- A person who maintains **old skills and talents**
- A person who thrives on the **arts**
- A person who has excellent **hand-eye coordination**
- A person who experiences all **five senses**
- A person who responds to the **experience of new information**.

For more reading:

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Donald Koepke, MDiv, BCC, is Director-Emeritus of the CLH Center for Spirituality and Aging headquartered in Anaheim, CA, having served as founding director from January, 2000 to July, 2008.

Before his directorship, he served as a parish pastor for 27 years and then as chaplain for two retirement communities within California Lutheran Homes. He is chair of the editorial board of "Aging and Spirituality," the quarterly e-newsletter of the Forum for Religion, Spirituality and Aging of the American Society on Aging. Nationally, he has engaged caregivers, health professionals and faith community leaders with the perspective that "Aging is a Spiritual Journey."

New and noteworthy

ZION XIV
OCTOBER 21 – 24, 2010
THE LODGE AT SIMPSONWOOD
ATLANTA, GEORGIA

Speakers: Commitments have been received from both the President of the LCMS and the Presiding Bishop of the ELCA to be with us for this event. They will each speak to the whole group and then share further comments with their denominational constituents.

Theme: The conference will explore the theme: “Firm Foundations: Theological Challenges of Pastoral Care in Contemporary Specialized Ministries.” Plenary speaker will be **Dr. Fred Niedner from Valparaiso University. Dr. Shauna Hannan, from the Lutheran Theological Seminary in Columbia, SC,** will lead Bible Study.

As in previous Zion Conferences, there will be workshops! Here are the 7 selected so far:

- 1 **Death & Dignity** — Daniel Rumflet
- 2 **System Response to Post Deployment from Combat** — Tom Waynick
- 3 **Caring for Specialized Ministers: One Task of the NC Synod** — Carla Lang
- 4 **Spiritual Progression: Loss and Recovery Values for Substance Abusers** — Peter Lundholm
- 5 **Mutual Conversation and Consolation: Approaches to Bereavement Care** — Peter Lundholm & Julia Shreve
- 6 **Understanding Ambiguous Loss** — Mel Jacob
- 7 **Missional Ministry: Intentional Spiritual Intervention in SPC** — Joel Hempel

Location: Seclusion in the Heart of Atlanta! **The Lodge at Simpsonwood** is a Christian adult and family retreat center nestled in the heart of metropolitan **Atlanta, Georgia** (www.simpsonwood.org). It is surrounded by 227 acres of woodlands along the Chattahoochee River with three miles of wooded trails. Designed to harmonize with nature, all facilities are within easy walking distance of one another.

Zion XIV Planning Committee:

Margaret Anderson
Evon Flesberg
Ben Moravitz
Chuck Weinrich
Bryn Carlson, Chair

GIVE SOMETHING BACK SCHOLARSHIP

Attention: any Lutheran who is in training to become a Chaplain, Pastoral Counselor, or Clinical Educator: The **Give Something Back Scholarship** Fund - at this time - has \$3000.00 available every six months for you Lutheran brothers and sisters who are in need of financial assistance as you journey through your professional training!

For more information, contact either the ELCA “Ministry of Chaplaincy, Pastoral Counseling, and Clinical Education” office, Theresa.Duty@elca.org or, the grant request may be sent to the LCMS office of “Specialized Pastoral Care,” Judy.Ladage@lcms.org.

Recent and upcoming events

LCMS

July 9-17, 2010 LCMS National Convention is held in Houston, Texas

Inter-Lutheran

October 21-24, 2010 Zion XIV takes place at The Lodge at Simpsonwood in Atlanta, Georgia

May 4-6, 2011 Lutheran Services in America (LSA) conference in Milwaukee, Wisconsin

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