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## The Role of the Faith Community Nurse in Fostering Spirituality in those with Alzheimer's Disease

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## THE ROLE OF THE FAITH COMMUNITY NURSE IN FOSTERING SPIRITUALITY IN THOSE WITH ALZHEIMER'S DISEASE

Alzheimer's disease (AD) strips individuals of so much that define who they are – their memories are gradually erased as if the “delete all” command on a computer was selected. It is easy to believe that the “loss of self” also means a “loss of soul as well” (Carson, Vanderhorst, & Koenig, 2015, p.87). However, we enter this world as spiritual beings and we leave this world in the same way. The ability to experience the Almighty definitely changes as the disease progresses but that ability to do so continues. Faith Community Nurses possess a unique opportunity to foster this connection in those with Alzheimer's as well as their caregivers who are members of the faith community in which the nurse provides service.

Those individuals with Alzheimer's, along with their caregivers, continue to have spiritual needs. For many people with Alzheimer's religious or spiritual experiences reside in their long-term memories and remain accessible until very late in the disease. Ancient memories of a parent praying with a child or singing hymns to comfort may date back to infancy and so are preserved in the brain well after verbal communication along with short term memory has been destroyed. Religious music continues to be one of the most powerful interventions for reaching those in the late stages of Alzheimer's. Music is stored in the brain through a complex neural network that preserves music when other areas of the brain are destroyed through AD (Mooney, 2004; Snyder, 2003).

This article discusses the many ways that the Faith Community Nurse is able to meet the spiritual needs of those with Alzheimer's (Carson, Vanderhorst, Koenig, pp.89-91).

Alzheimer's alters every dimension of life including the spiritual. The individual's ability to communicate what is spiritually meaningful begins to diminish along with all other cognitive functions. However this does not mean that caregivers should ignore the issue of spirituality and/or assume that the person with dementia is unable to respond to the spiritual (Beuscher & Beck, 2008, pp. 89-90). As a caregiver it is easy to experience a sense of futility when working with a loved one or with a patient in a facility. It is understandable that caregivers might conclude that it would be futile to even attempt to meet spiritual needs because the person under their care will not understand. Nothing could be further from the truth. Many individuals were exposed to religious beliefs, experiences, and practices beginning in infancy. Perhaps family members said nighttime prayers during this time— a prayer as simple as:

*“Now I lay me down to sleep, I pray the Lord my soul to keep. If I should die before I wake, I pray the Lord my soul to take.”*

Perhaps as a child the person with Alzheimer's heard family members sing religious hymns, or perhaps he/she was exposed to a religious rite such as Baptism and later to First Communion and Confirmation or perhaps the child's parents dedicated him or her to God. Perhaps the child experienced a Bar Mitzvah or learned prayers in Hebrew, Farsi or another language. These early experiences are imbedded deep within the brain and stored in the individual's long term memory. The person may not remember the name of their most recent clergy person or what faith tradition they belonged to, but these lapses do not guarantee that the person has forgotten God. Not only do many with Alzheimer's remember God, but will also respond to long-ago recited prayers and hymns. When the opportunity to actively or passively participate in prayer and singing religious music is offered, many of those with Alzheimer's readily join in with these activities (Carson, Vanderhorst, & Koenig, pp. 89-90)

A video clip, embedded within a larger video entitled *Memory Bridge* shows a vignette of Naomi Feil interacting with Gladys Wilson who has not spoken in two years ([www.memorybridge.org](http://www.memorybridge.org)). In the video, Naomi, a teacher and consultant on the care of those with Alzheimer's, moves very close to Gladys and begins to gently touch Gladys's cheeks –the way a mother would stroke the cheeks of a baby. Naomi draws upon Gladys's religious history and uses old church hymns to connect with Gladys. Initially, Naomi, while continuing to stroke Gladys's cheeks, sings the children's hymn, *Jesus Loves Me, this I know, for the Bible tells me so*. Although Gladys does not join in the singing, she opens her eyes and focuses intently on Naomi's eyes; Gladys also begins to clap her hands on the arms of her chair as well as on Naomi's arms! Although Gladys does not verbally respond her eyes remain fixed on Naomi's face. Naomi then asks Gladys if she will join Naomi in another song. Naomi begins to sing *He's Got the Whole World in His Hands* and when she gets to the second verse, Gladys begins to sing along! It is an incredibly powerful moment when at the end of the song, Naomi asks Gladys if she feels safe and warm, with Jesus and with Naomi – to which Gladys responds yes. This short video clip is a powerful example of how religious music can reach down into the soul of a person and bring forth a response even from someone like Gladys who appears non-verbal and uncommunicative.

The religious beliefs, practices, and expressions of faith that are cradled in long term memory can be tapped into long after short-term memories are gone, even during the last stages of Alzheimer's disease. Profound memory loss is commonly referred to as “loss of self”. However, it never means “loss of soul”. The soul remains and is accessible to caregivers.

The implications of this knowledge are hugely important for Faith Community Nurses who are working in churches, synagogues, temples, or mosques and are connecting the spiritual

and the physical in their approaches to care. These are the formal places where people go to pray and to honor God regardless of religious tradition. People look to their faith to be accepted, spiritually challenged and fed, and to receive answers and direction during the most difficult times of life. How are these needs met when the caregiver can no longer access the religious facility, feels ashamed of a loved one's behaviors, or is just plain overwhelmed by the demands of caregiving that he/she has no energy left to even consider attending a formal religious service? What can the Faith Community Nurse do to break down these barriers so that the caregiver as well as the person with Alzheimer's is still able to actively participate in his/her religious services? The answers to these questions are first addressed through heightened awareness on the part of the Faith Community Nurse as well as the pastor, rabbi, imam or temple leader that members of their religious group are passively rejected because there is no support and/or contingency plans to accommodate and welcome those members of the congregation with special needs.

Perhaps Faith Community Nurses could offer education to members of their religious tradition regarding the special needs of those with Alzheimer's disease or other types of dementia. The Faith Community Nurse should be actively involved in decisions and plans to support both the caregiver as well as the person with Alzheimer's. Questions such as: should the person with Alzheimer's or other dementia still be transported to church, synagogue, or temple and be allowed to participate in the religious service in whatever manner is possible for the individual?; how should challenging and possibly in- appropriate behaviors be handled?; are there strategies to allow the caregiver to freely focus on the service while others in the congregation attend to the needs of the person with Alzheimer's?; how can the person with Alzheimer's be cared for without disruption to the rest of the congregation?; how will we

manage incontinence? These are all questions that caregivers as well as religious leaders must confront. Considering the potential onslaught of those with Alzheimer's as the Baby Boomer generation races into "old age", it would behoove spiritual leaders to inform their congregations that not only are they a welcoming community to those who are cognitively intact but also to those who are cognitively impaired. The last thing that should happen is that family caregivers are "cut off" from spiritual comfort because their spiritual community does not accept or understand the special needs of those with Alzheimer's. But even if the religious community threw open their doors to welcome those with Alzheimer's disease, the issues that surround dealing with disruptive behaviors still remains.

### **Impact of Memory Loss**

Some suggest that memory loss leads to chaos in the soul and a sense of abandonment because it is memory that allows us to hold onto God's presence in our lives. We recall answered prayer; we remember calling out to God in pain and sorrow; and we remember God's response. Memory affects how we approach the future- we remember God's past with us and we trust that God will be with us in our future. So it would seem logical to conclude that the memory loss from dementia cuts the cords of continuity that are meant to sustain the soul until the last breath. But is this so? Young children and infants depend on loved ones for their sense of God's presence – why wouldn't this be true for adults whose cognitive and functional abilities are that of a very young child? It seems that another responsibility of the caregiver is to continue to represent God's love and grace to the person needing care. It doesn't matter that the "idea" of God is no longer a possibility for the person with Alzheimer's. The "reality" of love, concern, and care are pathways to God with or without cognitive awareness. Both caregivers and

communities of faith have the privilege and shared responsibility to help those with dementia to find their way home to God in the midst of the chaos caused by the disease.

How can these challenges be met? What can Faith Community Nurses and other caregivers do to help repair the spiritual connections and restore the way home to God? Actively using religious rituals and practices, talking about the beliefs of the person's faith tradition, praying with the person, reading from religious texts such as the Bible or the Torah – all of these activities are used by parents of very young children to create a foundation of belief in the hearts of their children. While the child cannot grasp the idea of a God, he or she can certainly sense the feelings of love and comfort that parents have when they talk about God. These conversations generally convey love, connectedness and acceptance – and lead to feelings of safety and security – exactly what parents want to convey and exactly what caregivers to those with Alzheimer's must do also.

Faith Community Nurses, possessing the core nursing skills of assessment, analysis, implementation and evaluation are in a perfect position to apply these skills to the need to minister to those with Alzheimer's as well as their caregivers. These skills can be utilized to determine ways to include the person with Alzheimer's as well as that person's caregivers in the continued worship of the congregation. In order to restore those spiritual connections, caregivers need to be flexible regarding their definition of spiritual needs. First, there is a need to explore the "meaning making" history of the person with Alzheimer's. When families are instructed about this, they are usually able to identify the activities and beliefs that were part of their loved one's spiritual history. For instance they will know whether their loved one regularly attended religious services; they will know that their father found spiritual solace from nature, or perhaps their mother connected with the Divine through music. Every person possesses a "meaning

making history”. By exploring that history, caregivers can arrive at activities that are spiritually significant for the person with Alzheimer’s. For instance, adult children might remember that their mother said the rosary multiple times every day but that she never used rosary beads; instead, she counted the beads of the rosary on her fingers. Perhaps for this person, listening to the recitation of the rosary on television, radio or a CD would be a great spiritual intervention drawing on old and very powerful memories.

Perhaps the family may recall that when Mom was in church, dad was usually involved in something outside – that he thrived on nature and found spiritual solace in the outdoors. This knowledge might suggest several “spiritual interventions” including regular walks outside, watching videos that featured the beauty of nature, or activities such as fishing and sightseeing. Meeting spiritual needs must be very flexible.

Sometimes the use of visual aids such as a Menorah, candles, the Bible, a rosary, or figurines of praying hands may stimulate the recall of retained memories linked to the soul. Beyond visual cues, there are other sensual experiences such as the smell of incense; fresh bread or even wine might unlock powerful meaning making memories. Sounds such as recordings of church bells, the shofar horn, organ music, the words of Scripture, or liturgy are all capable of eliciting spiritual memories and emotions. Religious music is probably the strongest bridge to the person’s spirit.

### **The FAST Scale and Religious Needs**

The Reisberg Functional Assessment Staging Scale (Table 1) explains relates the stages of Alzheimer’s’ Disease with approximate cognitive age and expected changes in patients’

functional behaviors and abilities. It can guide the nurse in meeting spiritual needs of congregants. (Reisberg, Ferris, & Frenssan, 1985).

Table 1

*FAST Scale: A Functional Assessment Staging Scale for People with Alzheimer's disease*

<b>Cognitive Age</b>	<b>Alzheimer's' Stage</b>	<b>Scale Stage</b>	<b>Patient's Functional Abilities/Behaviors</b>
		3	Mild Cognitive Impairment; decreased job functioning evident to co-workers; able to use compensatory strategies to maintain function (lists, calendars, references)
11 years old	Early	4	Problems in performing complex tasks of daily life or IADL's e.g. paying bills; balancing checkbook; planning and preparing complex meal; safety issues in use of stove and management of medications; difficulty structuring day; automobile driving deteriorates; <b>Able to perform basic ADL activities independently and with good quality; able to engage self in familiar recreational activities.</b>
5 years old	Late Early	5	Problems in choosing proper clothing; needs help to function in community, problems in sequencing in dressing activities; may forget to bathe; needs help in locating unfamiliar rooms and locations although able to learn with repetition; <b>Able to perform with fair quality familiar recreational and ADL activities with help for set-up of supplies and supervision.</b>
4-2 years old	Middle	6a	Requires physical assistance in putting clothes on properly; forgets goal of activity, requires consistent help to find unfamiliar rooms and locations when walking or wheeling; requires inconsistent assistance to find familiar rooms and locations when walking or wheeling; <b>Able to use hands to pick up and use ADL and leisure activities however unaware of goal of activity and will need help with sequencing –even if activity is familiar.</b>
4-2 years old	Middle	6b	Requires help in bathing properly; patient has problems adjusting temperature of water; may have trouble entering and leaving the bath; problems washing properly and completely drying self; may be aggressive to caregiver around bathing issues.
4-2 years old	Middle	6C	Requires help in bathing properly; patient has problems adjusting temperature of water; may have trouble entering and leaving the bath; problems washing properly and completely drying self; may be aggressive to caregiver around bathing issues.

4-2 years old	Middle	6d	Urinary incontinence occurs in the absence of infection or other genito-urinary tract pathology; patient has episodes of incontinence. <b>Frequency of toileting may decrease occurrences of incontinence.</b>
4-2 years old	Middle	6e	Fecal incontinence occurs in the absence of gastrointestinal pathology; <b>Frequency of toileting may decrease occurrence of fecal incontinence; Able to use hands to pick up ADL and leisure objects and use for a very brief amount of time.</b> Is unaware of activity goal and will need sequencing help, even if activity is familiar.
12-18 months	Late	7	Speech limited to about 6 words in the course of an average day; ambulation ability diminished; requires maximum assistance for dressing, bathing, toileting and grooming; <b>Able to make gross body movements in leisure activities such as hitting a balloon, catching a ball, kicking a ball.</b>
Newborn - 12 months	End	8a	Intelligible vocabulary limited to a single word, grunt or other sounds; ability to sit up lost; requires total assistance for dressing, bathing, toileting, and grooming; <b>Responds to sensory stimulation activity with change in rate of breathing, blinking, turn of head, etc.</b>
Newborn	End	8b	Ability to smile is lost; may show other facial movements and sometimes grimaces; ability to hold head up is lost.

*Note:* The Reisberg Scale is adapted from Reisberg, B., Ferris, H., & Frenssan, R. (1985). An ordinal functional assessment tool for Alzheimer's-Type Dementia. *Psychiatry Online*, 36(6), 593-595.

In *Stage 4*, when the person is considered “a great Fooler,” and functioning cognitively somewhere between eight and twelve years of age, those with Alzheimer’s can still draw on long-term memory and act in an appropriate manner during religious services (Beuscher, & Beck, 2008). Memory loss is not obvious to most people. Faith symbols such as a Bible, cross, Menorah, and/or religious pictures are still meaningful to the individual. He or she can actively participate in religious services and family caregivers should be encouraged to not only attend services themselves but to bring their cognitively impaired loved ones with them. The person

with Alzheimer's can also participate in activities within the faith community if they are highly structured, such as distributing hymnals to attendees at the beginning of the service and bulletins at the end of the service. Religious hymns are important "connectors" not only to the present religious service but to old and possibly very distant but well-engrained emotional memories. Reading and reciting Scripture and prayers draws on old memories and serves the same purpose for those with or without Alzheimer's disease. Prayer continues to be important for the person in *Stage 4* along with reminiscence about holidays, weddings, and other ceremonies with structured rituals that are stored in long term memory. The presence of Bibles, religious pictures, and hymnals are powerful symbols that allow the person to both draw on old memories while still receiving spiritual benefit from the service. In this stage, however, the person might also be experiencing grief over his or her loss of memory or ability to function independently. The person is still capable of insight and insight can prove to be very painful, as they may be aware of what is being lost. Beyond *Stage 4*, the person will forget the losses – that parents, a spouse or other significant individuals are gone. A Stage 4 person may seek the comfort that these people would have offered and when they are not available, may suffer. Caregivers can validate the loss and suffering but cannot take it away.

Religious professionals, including the Faith Community Nurse can be a source of great solace to those with Alzheimer's by making sure that all those in their religious congregations regularly receive communion or other sacraments. This is especially true for the person with Alzheimer's who is homebound– regular reception of communion maintains a link with the faith community. A Faith Community Nurse can make home visits and bring a spiritual message from the church community including communion. Additionally, the nurse will be able to assist the caregiver with managing the care of their loved one (for example, by mobilizing respite support).

In *Stage 5* when the person with Alzheimer's is functioning at the level of a five to a seven year old, he or she will likely display behaviors that are not appropriate in a formal religious setting. First of all, without supervision the person at this stage might dress inappropriately, i.e., putting on underpants over dress slacks or wearing a low cut dress that exposes part of the woman's breast. The potential for these behaviors places a responsibility on family members or other caregivers to supervise dressing. Additionally, the person with dementia might yell out inappropriate comments during the religious service – this type of behavior indicates that the family/caregiver should sit with their loved one either in the “cry” room that many religious facilities provide for very young children or close to the exit so that they can make a quick getaway if needed during the service.

In *Stage 6* when the person is functioning at the level of a toddler and displaying behaviors such as extreme restlessness, mood swings, and confusion, it may be difficult if not impossible for the person with Alzheimer's to participate in services. If members of the faith community are trained on how to relate to those with Alzheimer's, then they could spend time with the person during the service in a location separate from the sanctuary. This would allow the primary caregiver to fully participate in the service and to receive spiritual consolation and support.

During *Stage 7*, the last stage, the person with Alzheimer's is functioning at a cognitive and functional level of about 18 months to newborn. Most of the time, it is not possible for that person with dementia to attend a formal religious service. In this stage, he or she is losing the ability to walk and is totally incontinent. This is the time when family members, good friends and members from the church/temple could provide “sitter” services at home so that the primary

caregiver is still able to receive the spiritual support at church/temple that is so necessary to be a good caregiver.

### **Spiritual Needs of the Caregiver**

Being a family caregiver for a loved one at home is difficult. The commitment to faithfully provide care 24 hours a day over many years represents the embodiment of love. However, even the most loving caregivers need respite. They need to replenish their own spiritual, emotional and physical resources. The love of friends and family directed to the caregiver reminds the person that he or she is not alone and that there are others who can be relied on to help. Caring and spiritual responses from family and friends are specific offers of support. “Give me a call if you need any help” is not a valid offer and does little to make the caregiver feel “cared for”. Rather the caregiver who is usually stressed and overwhelmed needs “helpers” who offer concrete assistance. For example, “Mom, I will come over every Wednesday night and stay with dad so you can continue to go to choir practice.” Or “Dad, I know you like to play cards with your buddies a couple of times a month – let’s set up a schedule so that I can plan to be here with mom while you are out.” The Faith Community Nurse is a wonderful assistant to families who are trying to balance 24 hour care with other needs and commitments. Sometimes the Faith Community Nurse is able to pull together volunteers that are able to assist the primary caregiver in any number of ways such as offering to stay with the person with Alzheimer’s so that the primary caregiver can enjoy occasional needed respite.

Even with support, not every care giver is able to provide this level of care. Those who recognize that the amount of care required is beyond his or her physical and emotional capabilities should never be judged for a decision to place a loved one in a nursing home or other

facility. Until family and friends have walked in that caregiver's shoes and experienced the relentless demands of caregiving, all judgment should be suspended. The only appropriate responses from family and friends are offers of help and loving support. The recognition that a caregiver has reached his/her limit is not a sign of weakness or lack of love but a realistic appraisal of the situation.

Additional strategies to help caregivers through this process include providing a journal and encouraging the caregiver to keep a record of the caregiving experience and the spiritual understanding involved in those experiences. Writing can be a remarkable anecdote to stress. Writing allows the person to express frustration, anger, joy, and feelings of success, abandonment and other reactions that accompany caregiving. Visits from members of the person's place of worship, including the Faith Community Nurse are important times that let the caregiver know that that they have not been forgotten. Any connection coming from the caregiver's faith community serves as a powerful link that provides comfort, and decreases the sense of isolation that is so often part of the caregiver experience.

### **Summary**

The Faith Community Nurse has an important role to play in the care of someone with Alzheimer's as well as in the support of that person's primary caregiver. Spirituality continues to play an important role in the life of the person with Alzheimer's as well as in the life of his/her caregiver. The recognition of the importance of spirituality needs to translate into thoughtful strategies that revive and support a continued spiritual connection - not only for the person with dementia but also for the caregiver. Regardless of the unrelenting ravages of disease, spiritual needs continue and the extent to which these needs are met can powerfully impact the physical,

emotional and spiritual health of the caregiver while at the same time lovingly ushering “home” the person with Alzheimer’s.

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