

Dementia Related Diseases: Sensing the Sacred

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Looking into my husband's eyes I said, "We are losing a little of you every day. I am afraid and sad."

Cognitive dementias may destroy the brain, but not the soul. Disease-based dementia in any form is brain development in reverse. "Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred." How do you do that without words?

Next to the "C" (cancer) word comes the "A" (Alzheimer's) word (for this article, any cognitive decline associated with disease) which strikes fear in anyone's heart. Over time, a variety of debilitating cognitive illnesses hinder articulation of needs, wants, identifying things, and perception of one's place in space. Nerve cells erode or are erased resulting in regressive brain function.

The Slow Change of Declining Cognition

The slow change of declining cognition interferes with thought processes that affect personal characteristics, connectedness, and visualizing consequences of behavior. Resistance, a common challenging response, can be met with dignity, respect, love, and spiritual support. Communication, therefore, must be modified using greater appeal to the senses.

Beyond common forgetfulness, this silent epidemic changes cognitive patterns of remembering, thinking, and reasoning:

- Patterned forgetting appointments, directions, self-care, finding things, putting things in strange places, or difficulty in finding words
- Balancing checkbook, unusual decisions of generosity, or difficulty learning new things
- Social withdrawal, inability to recognize family or close friends, suspicion of others, inappropriate actions, or extremes of emotions of aggression or passivity

What does this mean for the caregiver? Increasing vigilance as life skills decline:

- Design consistent life pattern, calendar of events

- Directing
- Safely locking up valuables or potentially dangerous items
- Guide personal care
- Remove the car keys
- Assume financial responsibility
- Safeguard important papers
- Prepare and file legal documents while parties can sign
- Redirect inappropriate actions
- Accept increasing dependency
- Provide reassurance
- Maintain familiar faith traditions, rituals and activities
- Soothe and encourage

Providing Spiritual Care for those with Declining Memory

Providing spiritual care for those suffering from declining memory is challenging but possible. Much spiritual tradition is expressed verbally—preaching, teaching, reading, and singing relate to all communities of faith. Imagine being both blind and deaf. To actively support yourself, your loved one and family necessitates creating ways to express spirituality. Research indicates that human and divine essence is expressed not only by words but through the senses.

By what means of communication could one express faith, hope, and love? Think about the basic senses used to engage, develop and express one's personal spiritual journey and religious beliefs. A partial list includes:

Sight

- Art, such as banners and other forms of media
- Symbols
- smiling, nodding

Taste

- Partaking of the sacraments
- Partaking in meals of sacred importance

Hearing

- Congregational worship
- Singing hymns

Touch

- Adornment of vestments
- Partaking in rituals
- Hugging, shaking hands
- Giving an offering

Others

- Reading the Bible or other sacred writings
- Enjoying nature
- Participating in dramas
- Repetitious sacred words like the Lord's Prayer or the Apostles' Creed
- Attending a camp

As a chaplain in an Alzheimer's and Dementia residence, my most moving activity was the weekly 30-minute chapel service. The activity director and I arranged the chairs in short rows. Large print song books were provided. Singing was accompanied by CDs. The Lord's Prayer was particularly a group and individual activity. Participating in the Sacraments was particularly moving.

Sensory activities followed, using crafts with a religious motif, especially for seasonal religious events. During rounds, personal touch, reading, walking, sitting, eye contact, personal prayers, and playing harmonica hymns were part of spiritual care presence. "Being with" becomes more important than "doing for or doing with."

What are some spiritual lessons we can derive from declining cognition?

- Transfer hope toward the soul and spirit of the loved one as the family experiences decline due to the degenerating nature of the human condition
- Exercise creativity using the senses to express spiritual faith through ritual, pictures, smells, familiar religious music, taste of foods through Sacraments, and touch activities
- Practice love as presence, “being with” rather than “doing for”
- As a caregiver, maintain personal spiritual health

Caring for someone with declining cognitive function is challenging. There is no pain pill for observing slow decline. The grief seems endless. The effort seems non-rewarding. The brain and body degenerate. Concentrate on the indestructible spirit after the words are gone.

Due to his losses and illness, Job, the classic sufferer of Hebrew descent, became a burden to himself. His wife expressed her desire for his care to be finished. From Christianity, burden-bearing or caring for one another relieves the sting of self-burden. Commitment to care to the end is not done at the expense of the caregiver but because of others helping to share the load. Unhurried presence as a means of providing dignity may reveal a connection to the spirit from distant childhood and support.

Here are some ways a faith community can support the family and the loved one:

- Regularly visit.
- Ignore embarrassing behavior.
- Provide phone contact communication.
- Meals and help with household and yard work reduce the caregiving load.
- Take the loved one for an outing or stay while caregiver can have a break or run errands.
- Pay for respite care.
- Provide a mini-homebound church service.

There is no substitute for support. This disease is not a sprint; it is a marathon.

References

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