



IN TOUCH

HOSPICE OF THE VALLEY DEMENTIA NEWSLETTER

APRIL 2007

Spirituality and Dementia

SPIRITUAL CARE FOR THOSE WITH DEMENTIA

Some people with dementia might report their life experience with words like exile, mockery, despair, invalidation, humiliation, intimidation, loss of power, loss of self, loss of everything! Imagine yourself experiencing so many losses.

Speaking at a conference on Alzheimer's disease, an Australian Anglican named Christine Bryden said, *"Where does this journey begin and at what stage can you deny me my self-hood and my spirituality?...As I lose an identity in the world around me, which is so anxious to define me by what I do and say, rather than who I am, I can seek an identity by simply being me... As I travel towards the dissolution of myself, my personality, my very 'essence,' my relationship with God needs increasing support from you ...Don't abandon me at any stage, for we are joined at our spirits—not our minds or brains. I need you to minister to me, to sing with me, pray with me, to be my memory..."*

I need you to be a holy light for me, to affirm my identity and walk alongside me. I may not be able to affirm you, to remember who you are or whether you visited me. But you have brought God to me. If I enjoy your visit, why must I remember it?

Why must I remember who you are? Is this just to satisfy your own need for identity? So please allow God to work through you. If I forget a pleasant memory, it does not mean it was not important to me."

To provide spiritual care for those living with dementia, one need only to accept and unconditionally affirm another, to love, esteem and honor another who may be unaware of even self. To address the spiritual needs of those living with dementia we must allow people to be valued by deity for the sake of themselves, not what one can do, or say, or remember. This ministry is not for the faint-of-heart. It requires patience, perseverance, practiced skill and a sense of

being "made" for this labor of love; thereby, equipped for this work of grace. But then, this is the work to which each of us is called: the work of encouraging, comforting and affording peace to the troubled, including those living with dementia.

—*Hospice of the Valley Chaplain*

MEANINGFUL CONNECTION THROUGH POETRY

When I learned that one of my patients diagnosed with dementia loved music, painting and poetry, I was very excited. Perhaps I could get through to her on a very different level and have a brief meaningful interaction. Since her favorite poet was Robert Frost, I downloaded some of his poems from the Internet and read one of them on my next visit. She smiled at the end and said, "That was very nice." I could see that I had touched something inside her and hopefully brought her joy.

—*Hospice of the Valley Social Worker*

HOSPICE STAFF PROVIDE DEMENTIA CARE FOR THE BODY, MIND AND SPIRIT

Spirituality refers to beliefs and practices that connect persons with divine and meaningful entities beyond them; however, the term may be defined differently by each individual. People have described experiencing spiritual connections through nature, God/Divinity, prayer, relationships, finding a purpose in life and maintaining cherished values/beliefs. Since hospice care is devoted to holistic care, encompassing the body, mind and spirit, it is essential to understand the spiritual element of human experience.



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With respect to persons with dementia, it becomes increasingly difficult for them to maintain their lifelong spiritual practices. The gradual loss of communication ability results in suffering as a feeling of being disconnected, disintegrated and not at home (Norberg, 2001). When basic needs are met, it is this suffering that must be addressed. To quote Maribeth Gallagher, Dementia Program Director, "Dementia is a disease of the mind. It is not a disease of the heart and soul." With Alzheimer's, the rational mind is gone, but the intuitive mind is still active (Lefevere, 2004).

Furthermore, it has been reported that persons with dementia experience a sense of spirituality that remains longer than other memories (Campbell, 2004). For example, a woman with dementia may have no difficulty singing an old gospel hymn, even if she cannot remember her own name. Learning about a patient's spiritual history assists hospice staff in the development of meaningful interactions. These interactions may be the primary ways a person with dementia experiences their relationships with God, self, and the environment (Ryan, 2005). HOV staff, patient families and caregivers become essential facilitators for the person with dementia to access and maintain their lifelong spiritual connections.

Lefevere P. Caregivers find capacity for spirituality lingers. National Catholic Reporter. Dec. 17, 2004.

Norberg A. Communication in the Care of People with Severe Dementia. In Humbert ML and Nussbaim JF (Eds.), Aging, Health and Communication: Linking Research and Practice for Successful Aging (Mahwah, NJ: Erlbaum, 2001), pp.157-175.

Ryan EB, Martin LS, Beaman A. Communication Strategies to Promote Well-being among people with Dementia. Journal of Pastoral Care and Counseling, 2005;59:43-55.

AN ALZHEIMER'S PRAYER

Dear God, please help my family, friends and caregivers see me for who I always was, and not for what this disease has taken from me.

Help them to see that I want to be treated just like they do; with courtesy, respect and sensitivity.

Remind them, God, that although I may sometimes get confused, even act irrationally, these things can scare, frustrate and sadden me as much as it does them.

I don't want to be treated like a misbehaving child. Let them know that the best thing they can do during these times is to take my hand lovingly and hold it or give me a warm hug, for shows of love are universally understood.

Help my visitors to understand how grateful and appreciative I am when they come and spend time with me. I don't need presents, just the precious gift of love. And just because I may forget their name doesn't mean the love I have for them in my heart has changed. I feel it, and am comforted and warmed when I hear their voice, see their smile, or feel their loving embrace.

Let them know, God, that I don't like this predicament any more than they do, and that even though my needs are now different, I still want to be included in their lives because, if I lose my family and those dearest to me, then so too will go my will to go on.

I can deal with this disease because I have to, but I just need them to be a little more patient with me; a little more kind.

Lastly, help them, God, so we can get through this together.

—*Author Unknown*

TRY THIS

- Slowly recite a prayer or passage from sacred reading known to have brought this person comfort.
- Help with holding rosary beads and/or Bible.
- Assist with walking/wheeling outdoors to bask in the sunshine and smell the flowers.
- Share a favored comfort food.
- Allow for reciprocity by saying to the person, "Thank you for the visit. I enjoyed your company."
- Creatively explore other methods to bring peace or solace (readings, rituals, music, nature).