

An Invitation to Learn About Two Growing Pastoral and Congregational Needs

The Spiritual Care of Persons with Dementia and Choosing Advance Directives

Healthcare treatments and advances in medical technology have brought ongoing changes to ministry. Providing pastoral care to a church member who is ill more often now covers a long period of time as a chronic illness slowly descends into its terminal stages, as dementia increases significantly as a diagnosis or co-morbidity, as intergenerational care issues emerge and people are called upon to make end-of-life medical decisions for themselves or a family member.

When they turn to their minister they are seeking hope, guidance, answers, direction and a companion for the journey. For this a minister needs to know that there are resources accessible for them and for the congregation. As a hospice spiritual counselor with twelve years of experience ministering to people at the end of life, including many who live their final years in the haze of dementia, I am available to provide clergy and congregational education through preaching and forums.

Never Forgotten: The Comfort of Spirituality in Dementia

Dementia is a slow, irreversible, progressive, relentless disease process that gradually takes away a person's abilities to think clearly and rationally, to function as an adult, to care for one's self, to recognize the people in their life, to walk, to talk, to sit without support, even to smile. It is a long chronic disease that becomes terminal. Dementia is not a normal part of aging but it is on the rise in a dramatic way. While most causes of death have decreased in the past decade, dementia is up 71% and it is the only disease among the top 10 causes of death in America that cannot be prevented, cured or even slowed. In MA alone there are 120,000 people living with a form of the disease, many who for decades were active in their churches and communities. How do we spiritually and pastorally support them at this time in their lives?

As infants we have and express emotions very early on, so that within our first few months we show joy, calm, fear, sadness and anger. The emotions, these reactions to the world and the people around us, are our first lessons and responses. These first lessons are also not lost to the ravages of dementia. Our emotions, whether we feel safe or scared, calm or cross, are not lost in the haze of dementia. Emotions remain a language, a way of communication, for those who are even in the final stages of the disease. Acknowledgment and attention to the language of emotions is comforting, supportive and healing.

Within the realm of our emotions is our spirituality. As French Jesuit priest and philosopher Pierre Teilhard de Chardin reminded us, "We are not human beings having a spiritual experience. We are spiritual beings having a human experience." Our sense of spirituality, of what gives and has given meaning, value and purpose to our lives, yet is beyond and greater than us, remains even in the fog of dementia. Dementia robs cognitive functions but emotions and expressions of spirituality are never lost. Maintaining spirituality, the core values and meanings by which people live is connected to our emotions. Spirituality encompasses all that is our deepest self, and often draws upon our earliest and most significant memories that have shaped the person we have become. It is through important relationships and accomplishments,

our sense of community, what inspires us, what gives us hope, what brings us joy, what we value most in our life that we find our spirituality.

A Valued Conversation: Advanced Directives

Advance directives are pre-planned, written legal documents that help protect a person's rights of self-determination (the right to make one's own medical decisions, including the right to accept or refuse treatment). These documents are a person's requests concerning health care when they are not able to speak for themselves.

Over the past few decades there has been a cultural shift from paternalistic medical treatment to a consumer driven approach in which patients have control and choices to make for their healthcare, including end-of-life care. Dramatic medical and technological advances have both created options to choose from but making choices can be overwhelming and confusing without a solid foundation of what is involved in those choices.

We who are treasures in clay jars, in earthen vessels, we who are created in the image of God have been given a gift of abundant life. When we were still yet cradled in the waters of our mother's womb the days of our life were already written in the divine book of life. As the days of our life come one by one and add up to years, to decades, we know that we are mortal-that we are dust and that this gift of human life gives way to eternal life. How do we then - as people of faith- choose life when we are being attentive to the end of our life?

While a conversation on Advanced Directives is about the medical care of our physical body, the various medical procedures and actions, and the physical processes of illness and death, they are decisions that come from our spirituality, values and beliefs. It is as long-term advocate of improved end-of-life care Gwen London, D.Min. wrote "Dying is a spiritual process with medical implications, not a medical process with spiritual implications."

In other words, who we have been in our life will be who we are in our time of dying. The same religious practices, spiritual beliefs, ethics and values that have guided our life will guide the final chapter of that life. The more we can be prepared for this time, the more comfortable we and our loved ones can be as well.

Rev. Donna Vuilleumier is affiliated clergy at the Eliot Church (Natick) and has been a hospice spiritual counselor since 2003. She leads congregational forums, Super Saturday workshops, and a variety of community events on these two issues as an important part of her ministry. To learn more or to plan an event for your church, she can be reached at Donnav930@yahoo.com.