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When the Spirit Moves You

by Anita Darcey RN, BSN

Over 20 years ago I stood at the foot of the bed of my 19-year-old patient. He was a delightful teenager dying from Leukemia. He was surrounded by IV poles holding fluids, blood products, antibiotics, and antifungals. He wore an oxygen mask, was on a cooling blanket, and lay flat on a special therapeutic bed. As I said goodbye for the evening, he lifted his head from the pillow to make eye contact, and slowly lifted his arms, gesturing to the objects that surrounded him and whispered in his hoarse voice, “Anita, there’s more to it than this... there’s got to be more to it than this.”

His words challenged me, haunted me when he died alone in his hospital bed, and inspired me to begin a journey to fully comprehend their meaning. What has become clear to me is that essential to the holistic care of any patient is the understanding of spiritual suffering. Whereas biomedical science and research are the foundations of the care of the physical body, the compassionate response to spiritual suffering is the art of my nursing practice.

Richard Groves is an internationally respected scholar and teacher of end of life care, and the founder of the Sacred Art of Living Center in Bend, Oregon. I was privileged to have studied under Richard for five years, earning a certificate in spiritual direction. It was under his tutelage that I began to have words to express what I intuitively understood about the human condition as we deal with illness, and the eventuality of death. As a hospice chaplain for 25 years, Richard identified four kinds of spiritual pain: meaning, forgiveness, relatedness, and hopelessness.

Meaning pain is experienced when physical suffering causes the loss of purpose and meaning in one’s life. As disease takes over, and one can no

longer be in the world as one once was, there is often a crisis of identity that occurs. Everything of value seems to slip away. This is the moment that we can help our patients to identify those people, or things for which it is still worth living (Groves & Klauser, 2005).

When pain or disease causes one to feel incapable of participating in the world, there can be a complete loss of the familiar. One can feel unable to relate to the life that has evolved in the wake of illness, and relatedness pain can be overwhelming. We can ask the questions that help the patient to identify with whom they still feel connected, and to remember what matters most to him/her (Groves & Klauser, 2005).

For most of my career I have cared for those with life threatening illnesses. I have been at the deathbed of many, and I have been privileged to hear their stories. Forgiveness pain causes much distress for those who are struggling with the end of their life. Who do I need to forgive, and from whom do I wish to receive forgiveness? Intimate and personal, it can be difficult to have these conversations, but releasing the anguish that surrounds this spiritual pain is enormously freeing (Groves & Klauser, 2005).

The pain of hopelessness can be devastating. When one falls into the despair of seeing no hope for a future without suffering, there are often no words that we can offer to comfort. Physical touch, music, massage, and energy healing are frequently more effective in bringing relief (Groves & Klauser, 2005).

I bear witness to the beautiful, sometimes desperate lives of my patients. I recognize that there is an indomitable spirit, an uncrushable truth that resides within all of us. This spirit



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sustains us in our times of suffering, and gives us strength to fight our way out of misery. Spiritual direction is the most intimate heart-journey possible. I choose to practice my profession with respect for the depth of that which is “within,” and a desire to honor the whole person - body, mind, and spirit. If one is truly to be a practitioner of holistic nursing care, then the spiritual suffering of our patients must be recognized, valued, and ministered to with an open, accepting heart. The challenge is to expand our understanding of suffering, to see beyond the physical, and to fully appreciate the complexity of the human experience. Herein lies the secret to a satisfying professional life, full of hope and inspiration.