## Consider the Conversation, *PLEASE*Hospital Newspaper, August-Sept 2011

In the new film, making the rounds of hospital and universities, "Consider the Conversation: A Documentary on a Taboo Subject" (<a href="www.considertheconversatoin.org">www.considertheconversatoin.org</a>), filmmakers Mike Bernhagen and Terry Kaldhusdal have created a serene walk through a difficult topic: death. They follow the route of the contemporary end-of-life experience and illuminate mileposts and turning points along the way, gently encouraging us to see that we have become blind to the fact that few of us die at home where most of us say we want to.

There are many messages that stayed with me, like visionary palliative care specialist Dr. Ira Byock's reminder that the end of life involves the same dependency that the beginning of it does and it's time we accept that and support it. Scenes of the flooding in New Orleans illustrate the notion that "hope is not a plan."

When Martin Walsh, a doctor dying of ALS, shares his list of "100 Things" (http://articles.latimes.com/2009/jul/26/opinion/oe-welsh26) "I began to make my own list. But when Journalist Stephen Kiernan says, "Every year I pass the anniversary of my death. It won't matter to me, but it will to my family," I woke up.

I have to die. My death is required. One day my time will come and I will have to experience it. I—my spirit, my consciousness, my soul, whatever energy it is that animates my body—will leave my body in the time it takes to say "Ahhhh," and I will be dead. No amount of money, connections, good medical care, and prayers for a miracle or wishing that I stayed alive just a little longer will stop my death.

At this moment I sit in a comfortable seat in apparent good middle-aged health so I don't know when I will die, how I will die, what will cause my death, if I will die suddenly or slowly, sooner or later. I don't know where I will be when I die or who will be with me when I die. I don't how I will feel or think about dying when death finally comes to collect me. But I do know how I feel about it right now.

In my total, if cavalier, acceptance of the truth of my death, I also accept the similarly profound reality that I could die tomorrow as well as forty years from now when I am 102. What if tomorrow is the day and instead of dying I am rescued from the arms of death by an efficient emergency room crew but damaged so badly that without life support I will die? What if death greets me?

My dying time will involve doctors, a hospital, paid caregivers, maybe even a nursing home, hopefully a hospice, and ultimately countless strangers with varied attitudes and beliefs about the meaning of death and whether to support or fight it and to what degree.

Whenever my time for dying comes, it will involve my family and many people who love me. They will want to hold on to me and not let go until they have done everything they believe they can to keep me alive longer, whether or not I am living the life I would want to be living. This fact I also accept, and it scares me.

We read about these situations all the time. Some of them make it to the front pages of newspapers and magazines, even to prime-time television. The cases of Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo, who were all under the age of 25 when death reached out and left them on life support, were delivered to the Supreme Court of the United States by expensive attorneys representing loving family members in terrible distress before they could be released from what many agree to be a fate worse than death.

I want to prepare in all the ways I can, knowing that I can change my mind and the decisions reflected in my legal documents any time I want. I want to prepare the people who love me so the experience of my death is not as traumatic and agonizing as it will be if I do not prepare them, especially if they face medical decisions to stop treatment that will directly result in my death.

Studies of surrogate decision makers reveal emotional suffering akin to post-traumatic stress syndrome resulted when end-of life decisions had to be made without the advance directions of the patient. One study

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discovered that ventilator patients remained on life support 40% longer without previous discussion of endof-life wishes with their surrogates than those who had a prior conversation about the patient's wishes. I don't want to put my family through that.

When I asked my big sister if she would be my healthcare proxy she answered, "You're my baby sister. I don't want you to ever die." I said, "Then you can't have my power of attorney for health care." Next I called an old friend who experienced a conflict at the end of her mother's life that nearly ruined her family. She was honored to be trusted to ensure my choices would be heard. I made my sister her backup, to include my sister on my team and cover a situation that would prevent my friend from serving as proxy.

After securing someone I trust to watch over me, I wrote out my choices for care then invited them to sit and listen to what I wanted. I ordered a pizza, opened a bottle of wine, put a box of tissue on the table and had the conversation about what is important to me when death comes.

"First, I want no disagreement about what I've written. If the medical professionals want to try more treatments, you must weigh the benefits against the burdens and decide according to my express wishes.

When my time comes, I pray that the medical professionals who care for me have the skill and wisdom to tell me that I have reached the limit of my life and give me, and the people who love me, some time to prepare and to experience the compassionate support of hospice care.

I want to spend the time I have left living in my own home, or somewhere very peaceful, filled with comfort for my loved ones and visitors, and light coming through windows that open to the sights and sounds of nature.

I want to hear to sweet music and playful laughter and feel the energy of life swirling around me.

I want to be kept clean and dry, dressed in soft, pretty clothes with fluffy sox on my feet, and my glasses on my face in case I open my eyes.

I want to be gently touched, stroked with warm lotion, feel the arms of my loved ones around me and their hands in mine.

I want to leave when I am called to my eternal home and not held back artificially, even though the people who love me will want to keep me longer.

My burial plan is already arranged, instructions written, and money set aside for a celebration of my life so that my family will not have to deal with such distracting business on the day I die."

A bittersweet sadness fills me as I think about the great waves of sorrow and grief that will wash over my loved ones after I leave, and I dearly hope the long, complicated process of grieving is productive and peaceful, not painful for them. I pray they can use their passages through grief and mourning as a map to learn how to cope with and live beyond all the losses ahead, especially the unfathomable losses that result from violence or nature.

My sister doesn't like it when I talk about my death. She reminds me she's 15 years older than I am and she will probably die first. When she says this, I take her hand and say, "Dolores, one of us will die first. One of us will sit at the bedside of the other and have to let go. Until then, I want you to know I love you. I am lucky that you are my sister and you're the best sister I could ever have." We cry, we hug then we eat another piece of pizza.