



ART OF CARING

MAYBE DYING IS LIKE ‘THE BLUES’

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On a recent Friday night, I found myself at an intimate music venue outside of Cleveland listening to a female singer and three male musicians performing “the Blues.” She was middle-aged, wearing glasses and an outfit that probably did not follow any fashion rules. She was full of energy and movement, seeming at once both restrained and free. Her voice was booming and rich and she truly played it like an instrument. The bass player looked like a young James Taylor wearing an Irish Darby, expressionless the entire time, with cloudy eyes that seemed to have no reason to see. The drummer had black hair pulled back in a short bun, never breaking a sweat. The keyboard player, on the other hand, was sweating profusely with his eyes mostly squeezed shut tightly and was exhibiting a variation of multiple grimaces despite seeming to be in no pain at all.

Maybe it was the two glasses of Malbec. Maybe it was the small pepperoni and four-cheese pizza. Maybe it was the compassion fatigue at the end of a long day at the end of a long week. But I found myself thinking about a friend who is a retired physician, but more importantly, is a beautiful blend of a Jewish sage and a Celtic Anam Cara. She talks about her “committee.” All of the various aspects of her personality and ego have been personified and exist in her mind as a committee of beings who continuously argue and struggle to be the dominant expression to the world of who she is at any point in time. She has found this extremely helpful in understanding and attempting to modify her own behavior. It can actually be quite funny to hear her refer to her “committee” when she is talking to you. However, I have learned to use this concept when I am trying to understand what is unfolding in front of me as I attend to someone’s dying.

A significant amount of my time as a hospice physician is currently spent educating and

supporting the loved ones who are trying to accept and understand the death of someone whom they care about deeply. The process of dying can sometimes be peaceful and beautiful, but oftentimes, it is noisy, hectic, and uncomfortable to witness. We medical folks try to categorize and name what we are seeing, but we really don’t have much of an understanding of what is actually happening. Despite our tremendous accomplishments in medicine, including the use of technology, we remain quite baffled and incompetent in conceptualizing the dying process. There is no Krebs Cycle equivalent that helps us schematically explain what is unfolding in front of us. Interestingly, our Egyptian forefathers were quite the opposite, and in 1240 BCE “published” the *Egyptian Book of the Dead*, where they described their understanding of the many stages of dying and death. Some say they were able to identify up to 40 separate stages as they observed the dying process. When I am trying to explain to families what they are witnessing, and I am struggling to manage, I always give the caveat that dying is mostly a nonphysical process. Obviously, there is a physical component as the body shuts down. However, most of what is occurring is not measurable nor predictable. I call it “spiritual,” but there are certainly strong components of the emotional, psychological, and relational aspects of who we are (ie, “different members of our committee”).

So what is it that we see at the bedside of our dying patient? We see alterations in vital signs, of course, with fever and usually some manifestation of sweating or clamminess. Breathing patterns are highly variable, often with periods of rapid breathing alternating with periods of apnea, ultimately joined by the cacophony of upper airway secretions aptly known as the “death rattle.” Purposeful and nonpurposeful (to us) movements of the body, including persistent attempts to sit up or even

get out of bed, removing of sheets and gowns and tubing, reaching up and towards, and leg movements that seem to be locomoting somewhere...all of these, we wrap up neatly and call "terminal restlessness." The mouth and eyes, however, are what capture our attention. The eyes can be open or shut, often unexpectedly. Ancient wisdom declares "the eyes are the window to the soul," and that is no truer than in the eyes of a dying person. It is hard to describe, but once you see it, you will not forget. Looking deceptively at you, but actually looking through you. Cloudy, misty, fixed...often focused for some reason upward and toward the corner of the room. It is not the dry mucosa or the weakening jaw muscles that bring our focus to the mouth. It is the verbiage. "Symbolic language" as the dying person attempts to put into human language what they are experiencing. Themes such as traveling, departing, completing tasks, and taking tests often serve as encrypted clues to what the soul/spirit/lifeforce is trying to do, despite the impediment of the physical body. Verbal acknowledgment of the real presence of deceased loved ones, if not written off as hallucinations, are a powerful gift given to the loved ones still living gathered around the bed. These spiritual beings, called "psychopomps" by the historians, are believed to be the those sent to help the dying on their journey. It turns out that these liminal escorts are often female and often the dying person's mother. Sometimes the most melodic and nonsensical words and sounds come forth, delivered with such conviction that we as caregivers feel inadequate.

So it was that I found myself increasingly absorbed by the sounds, and the movements, and behaviors of the singer and the three musicians performing "the Blues" that Friday night. The songs were mesmerizing, taking me on a roller coaster ride of emotions and primal instincts and calling to the hidden places in me. I noticed, and then could not un-notice, that each of those four people on stage were able to contribute to this production despite being totally and apparently unaware of anything or anyone else on the stage or in the audience. It all seemed somehow so familiar. The intent and power of the runs of scat coming from the

singer's mouth. The eyes of the base player. The gyrations of the drummer and keyboard player. The constant beat to which they were all responding, but which I could not comprehend. The moment of clarity came when I heard the following lyrics, "I'm going to see my mother... she said she'd meet me when I come...I'm going over Jordan...I'm only going over home...I'm just a'going over home."

This is what the dying do! I see it all day, every day. When it is my time on the deathbed, as my body is shutting down, I suspect the members of my committee will take their turns making themselves known as the light slowly gets brighter. I'm sure that my contortions and vocalizations will confuse and trouble my caregivers. I'll become the beat that they can't hear. Somewhere, Etta James will be singing "I'm just a poor wayfaring stranger," and I'll just be going over home. ●

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