

Essay/Personal Reflection

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An elegant woman in her late 60s, Marianne (name changed for privacy) exuded a special grace. That grace, however, was tried and tested as she battled terminal pancreatic cancer, which was spreading throughout her body. When Marianne and I first met, she was a new hospice patient, and I—a biomedical researcher at Stanford University, fresh out of college—was volunteering with her Northern California hospice provider. At the time, she retained many of the qualities that had defined her in health and vibrancy, but Marianne was suffering—physically, mentally, emotionally—with the implications of death and dying. When I helped nurses turn and reposition her, she exhaled groans of exhausted pain. (My medical colleagues would manage that pain, with timely medication and personal support.) When the purposeful pace of caregiving had slowed, though, Marianne and I sat together. I would hold her hand, listening to questions for which I had no answers.

In those moments, Marianne was freed from expectation. She was free to show pain, confusion, and weakness without judgment. But often, she would softly speak a few caring words, which rattled through my skull every time:

“You’re too young for all of this.”

My regular response was one of loving contradiction: “Absolutely not. It’s a privilege to be with you as you go through this. You’ve had a hard few weeks; but you are not alone.” However, those exchanges often led me to an uncertain self-examination.

“Too young for what, exactly?” I would ask myself. “Death?”

To be sure, Marianne’s words made perfect sense. She was not, after all, facing death as some philosophical inquiry. She was facing the pain of metastatic cancer, and the end of her life. Why would such a caring woman ever want anyone—let alone this 22-year-old man—to shoulder any of that burden? Marianne’s words were, and always will be, a loving act of mercy.

But death and dying are not *exclusively* personal. Death and dying are universal. So, to this day, I cannot escape the question: “Why am I too young to think about death and dying?” Through reflection and experience, I’ve formed the rough sketch of an answer. Or rather, I have reframed the question entirely, and in doing so, reminded myself that dying is, in fact, still about life.

The idea that young, healthy people should not burden themselves with mortality is part of a much broader Western attitude, one in which death itself is pathologized. For our culture, conversations of death and dying are rather like policemen, showing up at the door of a vibrant party. Life is meant to be lived with vitality, so why waste time talking of death? There is an eternity for that, no?

Our culture values healthy bodies; it exalts the human will not only to survive, but to thrive. No wonder, then, that people and communities often neglect this important topic. Our obsession with life has made us avoid discussions of death as if they were, well, the death of us.

But one cannot ignore such a deeply human fact without consequence. While a person is alive and well, while their kidneys are functioning and they remember what day it is, those ramifications may seem irrelevant. But the death conversation cannot go ignored forever. We do not have a choice.

What does “the death conversation” even mean, though? This leads to my reframed question: What do we talk about, in end-of-life care, when discussing death? Why should everyone, not just the dying, take part?

When we talk about death in hospice care, one might imagine a melancholy room, filled with hopeless and defeated people. One’s imagination, though, would be somewhat inaccurate. The best and most productive conversations about death are not depressing; they are difficult, but people walk away with greater peace and preparedness. When we discuss death in hospice, we get to the bottom of things, probing thoughts and conflicts that should not go unaddressed at any stage of life.

A patient, despite all efforts, is dying. How does that *person* want to spend his or her day, knowing this? What is that person’s favorite part of himself or herself—whether it be wit, piano-playing, a warm personality—and how can we maintain that as long as possible? What traits and activities are expendable and which are necessary for a meaningful existence? What does a good day look like? A bad one? These questions are not mere rhetoric; their answers provide a rough blueprint for a quality end of life.

Recently, my own grandmother entered hospice care. She is a diabetic with a history of poor blood sugar maintenance. A rhinovirus infection had led her to bouts of hospitalization, kidney failure, intermittent delirium, fatigue, edema, and fluid in the lungs. For days at a time, she struggled to maintain conversations or communicate at all. After my grandmother's physician recommended her for hospice, my family felt this was the best direction. But how could we know?

Long beforehand, in those ostensibly awkward death conversations, my grandmother had given clear directives: she did not want to be intubated, placed on dialysis, or kept alive by invasive and intensive medical intervention. She was almost 90 years old and had lived a good life, with a late husband, two children, and three grandchildren to her name. Life, for her, was not about living longer; life was about spending her last days in comfort with family.

My grandmother valued independence and the ability to live life on her own terms. A good day was a restful one, where she could play the piano and see her grandchildren. A bad day was one spent in the hospital, with needles and tubes and beeping and humming, laying tired and confused in a strange bed.

My family was aware of those desires, precisely by giving the death conversation its due attention. Yet even with that knowledge, her situation was difficult to manage. Could the kidney failure and edema be stopped if we sent her back to the hospital? Had grandma simply been discharged too early? Had physicians merely been impatient with an elderly woman's physiological puzzles? Had we given up?

My grandmother's narrative is, at present, still ongoing. Knowing her desires has not made things simple. Dying, itself, is never simple. There are still questions to be asked and nuances that smudge the lines of advance directive. She didn't want dialysis—but what if it lasted just a few days? She didn't want a ventilator—but would she tolerate oxygen tubes? End-of-life conundrums can be tough. But these questions, these conversations, have nothing to do with death. They are conversations about life, and what

a good life looks like when mortality is no longer an abstract idea. Those dialogs, however difficult, are helping give my grandmother her best life, right now.

The physician-writer Atul Gawande sums things up aptly: We in medicine and society, he writes, “have failed to recognize that people have priorities that they need us to serve besides just living longer” (Gawande, 2014). But we, who are young, healthy, and coherent, also have a simple solution to that failure, one that holds life-giving consequence: “The best way to learn about those priorities is to ask about them” (Gawande, 2014).

For Marianne, I'm happy to say, the right people were there to have the right conversations. In a calm and lucid state, made possible by caring hospice professionals, Marianne looked out around her backyard. The afternoon sun had left a warm haze over the red patio; she smiled softly at the quiet, comfortable world she loved so dearly. Turning back to her hospice physician, she asked, “When the time comes, do you think I can die out here?”

“Are you serious?” he said in surprise.

“Yes.”

Marianne spent her last days surrounded by friends and family, doctors, and nurses who cared deeply for her. Even more so, she had peace, comfort, and control—as much as possible for one with metastatic cancer. She still faced painful hardship, but until the last moment, her life was her own.

Tough conversations and vulnerable moments have helped remind me what I do for the dying: I help them live. Whether for my own grandmother, or a complete stranger, I know exactly what the death conversation means.

It means life.

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Reference

Gawande A (2014) The best possible day. *New York Times*. Available from <https://www.nytimes.com/2014/10/05/opinion/sunday/the-best-possible-day.html>.