And now, weak, short of breath, my once-firm muscles melted away by cancer, I find my thoughts, increasingly, not on the supernatural or spiritual, but on what is meant by living a good and worthwhile life — achieving a sense of peace within oneself. I find my thoughts drifting to the Sabbath, the day of rest, the seventh day of the week, and perhaps the seventh day of one’s life as well, when one can feel that one’s work is done, and one may, in good conscience, rest. [Sacks, O. (August 14, 2015). Oliver Sacks: Sabbath. Sunday Review, New York Times.]

What Four Icons, Emmanuel, Maynard, Sacks and Kalanithi Have to Contribute to Our Creative Conversations about Good Dying

The 1983 President’s Commission Report on Health Care Decision Making recommended the model of shared decision making over the Hippocratic/paternalistic model and the patient sovereignty model. In recent years major forces in the U.S., including the current HCAHPS patient satisfaction scores, have resulted in many clinicians abdicating their role in treatment decisions and capitulating to patient preferences/demands. Too often these choices result from deficient knowledge, unrealistic expectations, fears, etc.

In the last two years several very public figures have engaged media attention by sharing their preferences about how to confront aging, serious illness, and anticipated death. Given the moral heterogeneity in the U.S. and the lack of consensus about the role aging, suffering, illness, dying and death play for humans: evils to be avoided at all costs, necessary evils to be suffered stoically, or paths to our transformation and flourishing, what guidance can any clinician, ethicist or sage offer?

I share the following questions for your reflection and discourse.

1. In his new book, *The Road to Character* (2015), David Brooks focuses on the deeper values that should inform our lives. Responding to what he calls the culture of the Big Me, which emphasized external success, Brooks challenges us, and himself, to rebalance the scales between our “resume virtues”— achieving wealth, fame, and status—and our “eulogy virtues,” those that exist at the core of our being: kindness, bravery, honesty, or faithfulness, focusing on what kind of relationships we have formed.
   a. What role can the challenges of aging, suffering, illness, dying and death play in our lives? Are they necessarily evils to be avoided at all costs?
   b. Might they be invitations/opportunities to focus on what really matters and to cultivate the virtues that give meaning and purpose to our lives?
   c. We often hear that suffering can “make” or “break” us. How can professional healers help those who are suffering use their experiences to become more integrated and whole?
2. Do health care professionals and chaplains working with individuals experiencing aging, suffering, illness, dying and death have an obligation to “journey” with them as experienced and wise guides? Is it ever appropriate to make a recommendation or to challenge an expressed preference? Is it obligatory to do so? Do any of us believe we are qualified to be “wise guides”? Should we be?

3. The last of Erik Erikson’s psychosocial stages is ego integrity versus despair. Universal spiritual needs are meaning and purpose, love and relatedness, and forgiveness. What role should clinicians play as individuals struggle with questions about their lives’ meaning and worth?

4. What role do/should clinical ethicists play in informing conversations and decisions about treatment and care for those experiencing aging, illness, suffering, dying and death?

5. Given the coming silver tsunami (mass geriatric society) these questions assume a special urgency. Is there a better way to think about aging and death than enemies to be conquered? [Think war on aging and death...] When we think about human flourishing... what do we do with the assaults related to aging, illness and death? We live in a society that hardly reveres its elders. Should we be part of challenging what we message to older and seriously ill brothers and sisters?

Ezekiel Emanuel  
That's how long I want to live: 75 years.  
I am sure of my position. Doubtless, death is a loss. It deprives us of experiences and milestones, of time spent with our spouse and children. In short, it deprives us of all the things we value. But here is a simple truth that many of us seem to resist: living too long is also a loss. It renders many of us, if not disabled, then faltering and declining, a state that may not be worse than death but is nonetheless deprived. It robs us of our creativity and ability to contribute to work, society, the world. It transforms how people experience us, relate to us, and, most important, remember us. We are no longer remembered as vibrant and engaged but as feeble, ineffectual, even pathetic. [Emanuel, E.J. October 2014. The Atlantic Monthly. Why I hope to die at 75].

Brittany Maynard  
In April, I learned that not only had my tumor come back, but it was more aggressive. Doctors gave me a prognosis of six months to live. After months of research, my family and I reached a heartbreaking conclusion: There is no treatment that would save my life, and the recommended treatments would have destroyed the time I had left. I considered passing away in hospice care at my San Francisco Bay-area home. But even with palliative medication, I could develop potentially morphine-resistant pain and suffer personality changes and verbal, cognitive and motor loss of virtually any kind. Because the rest of my body is young and healthy, I am likely to physically hang on for a long time even though cancer is eating my mind. I probably would have suffered in hospice care for weeks or even months. And my family would have had to watch that.
I did not want this nightmare scenario for my family, so I started researching death with dignity. It is an end-of-life option for mentally competent, terminally ill patients with a prognosis of six months or less to live. It would enable me to use the medical practice of aid in dying: I could request and receive a prescription from a physician for medication that I could self-ingest to end my dying process if it becomes unbearable.

I quickly decided that death with dignity was the best option for me and my family. [Maynard, B. November 2, 2014. My right to death with dignity. http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/index.html]

Oliver Sacks
It is up to me now to choose how to live out the months that remain to me. I have to live in the richest, deepest, most productive way I can. I feel intensely alive, and I want and hope in the time that remains to deepen my friendships, to say farewell to those I love, to write more, to travel if I have the strength, to achieve new levels of understanding and insight. I cannot pretend I am without fear. But my predominant feeling is one of gratitude. I have loved and been loved; I have been given much and I have given something in return; I have read and traveled and thought and written. I have had an intercourse with the world, the special intercourse of writers and readers. Above all, I have been a sentient being, a thinking animal, on this beautiful planet, and that in itself has been an enormous privilege and adventure. [Sacks, O. February 19, 2015. My Own Life. The New York Times.]

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Paul Kalanithi
Kalanithi’s diagnosis is both a death sentence and an opportunity—albeit an unwanted one—for the kind of introspection that many of us claim to want but that never seems possible unless forced by tragedy.

His decision to go to medical school, he writes, was an effort “to forge relationships with the suffering, and to keep following the question of what makes human life meaningful, even in the face of death and decay.” Krug, N. January 9, 2016. An affirmation of life in the face of death. Book World. The Washington Post, C1, 4.

My brother arrived at my bedside. “You’ve accomplished so much,” he said. “You know that, don’t you?” I sighed. He meant well, but the words rang hollow. My life had been building potential, potential that would now go unrealized. I had planned so much, and I had come so close. I was physically debilitated, my imagined future and my personal identity collapsed, and I faced the same existential quandaries my patients faced. The lung cancer diagnosis was confirmed. My carefully planned and hard-won future no longer existed. Death, so familiar to me in my work, was now paying a personal visit. Here we were, finally face-to-face, and yet nothing about it seemed recognizable. Standing at the crossroads where I should have been able to see and follow the footprints of the countless patients I had treated over the years, I saw instead only a blank, a harsh, vacant, gleaming white desert, as if a sandstorm had erased all trace of familiarity. Kalanithi, P. 2016. When breath becomes air. New York, Random House, pp. 120-121.