

Turning Points and Talking Points on the Road to End-of-Life Decision Making

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For the first time in the history of humanity there is an entire generation living beyond 85 years of age. They are the survivors of their kind, the winners of the race to outlive their peers, their loved ones, and sometimes even their children. They are the last to die. They have survived the fatal diseases that claimed the others, sometimes on artificial life support.

This generation, with an estimated 100,000 centenarians, was born before 1925. They have lived through Suffrage, the Depression, the Dustbowl and The Great War. They know at least 18 of our 44 Presidents. During their long lives technology advanced from the first electronic radios, TVs, and blenders to space travel, microwaves, computers, cell phones, digital cameras, iPods, and Skype, while medicine evolved from chicken soup and cool cloths to CPR, feeding tubes and ventilators.

They've been retired for 20 to 40 years trying to cope with their mounting personal losses, loneliness, multiple chronic diseases, declining health and disability. They face dying and death in ways they never dreamed of.

While this cohort accounts for nearly 30% of all deaths, they have no role models for making the end-of-life decisions that modern ways of dying have come to necessitate.

Their values and beliefs about death were formed in the early half of the last century, when life, and medicine, was simple. Death was fast and people who were dying were supported by family and neighbors through death. Even though many of these sturdy elderly have lived for years—or decades--in declining health, they won't talk about dying because they believe it's between them and

God. For these weary travelers, "I want to go home" is the only advance directive they know.



Author Loretta Downs and her mother Anna Piazza Schenk at age 90.

Future in Shadows

"End-of-life decisions" is not in their dictionary. Discourse on these matters becomes complicated because family members are hobbled by geographic or emotional distance, discomfort, unwillingness, denial and fears over initiating a conversation about death.

Some of these formerly independent women and men are completely alone, by design or circumstance. As a result, an increasing number of the frail elderly are being admitted to hospitals with no one authorized to speak for them, no written instructions to guide care, and no mental capacity to make decisions: we named them the unbefriended. New ethical issues and legal dilemmas proliferate.

My mother's end-of-life was 15 years long. It began the day my father died and she became involuntarily dependent upon her children to fill the roles he had played in her life throughout their 61-year marriage.

We managed relatively well and her health continued to be good until 1998, when she was 86. Between that year and 2006 she spent two years in an independent living facility and six years in a nursing home during which she (we) experienced twelve emergency room visits, five hospitalizations—and countless meetings with medical professionals.

Although those major events were radical turning points in her health status, with each change giving us a green light to open a conversation about future planning, we did not. All of those distinct opportunities to talk about our mother's goals of care with the help and guidance of the medical professionals with whom we came in contact were missed because no one broached the subject.

We stumbled from crisis to crisis, tripping over our discomfort at using "The D Word" despite an obvious, progressive decline toward her inevitable death. We needed our medical professionals to recognize these turning points and to use them to our advantage and give us the opportunity to talk about the various ways to support our mother's life—and give her the care she wanted at the end of it.

At Peace

It was the 2005 Terri Schiavo case that brought my awareness to the potential tragedy awaiting us, and that gave me courage. My mother was 92 by then. One day we were together in her bed sharing a cup of coffee with ice cream in it, when I casually asked, "Do you ever think about the future, Mom?"

She looked straight at me and replied, "I'm living my future."



Photo credit: Todd Hochberg

I gazed into her eyes, the same ones that define my face, and asked tentatively, "What if something happens to you and you can't talk. What do you want us to do?"

She slowly turned her head forward, stared at the wall covered in photos and greeting cards, and said softly, "You girls will know what to do."

Not long after that day when my mother gave me and my sister her complete trust to do what was right for her, she was found unresponsive by the aide delivering lunch and was sent to the hospital. She could not be roused to eat or talk, though a battery of tests showed no reason for the condition. A few days into this semi-conscious state, an unfamiliar doctor took me into the hall and crisply said, "Your mother needs a feeding tube or she'll starve to death." I took a deep breath, let tears flow, and calmly replied, "Let's call hospice instead."

Within what seemed like minutes, a hospice nurse was in her room explaining what I might expect of the dying process and the services they would provide along the continuum. Mother was returned to her home at the Fairmont Care Center and I moved into her room with an air mattress to keep vigil. Three days later she sat up and asked, "Where's my lunch?"

Finding Peace

She thrived as a hospice patient. The added attention from the compassionate hospice

workers, the nursing home staff and her family were sufficient reasons to “keep on going” as she liked to say. After three months she was discharged.

Oddly, six months later the exact same scenario repeated, the only difference being that when she was discharged, my mother was happy for the first time in her life. She had used her time in hospice, as had I, to make peace with her life. She told me she was happy.

During the next four months we cared for her with massive doses of love and time and sweet treats. Then she had a stroke. In the emergency room her face and right arm were slack but the grip of her left hand on mine was like a vise. She was afraid. She knew what had happened but she did not know what would follow.

A doctor examined her and asked me some questions. He wanted to admit her to the hospital for tests but I refused, choosing hospice one more time. Mother let go of my hand. We returned to the Fairmont Care Center and moved into the Chrysalis Room, which I wrote about in the November issue of Hospital Newspaper, where she was supported, comforted, cared for by loving hands and companioned by people she loved for eight days of vigil. She was home and she was ready to die.

Although I know I made the right decision for my mother, I wish she had been able to tell me her end-of-life decisions the way I am able to tell my health care proxy about mine. What she and her children desperately needed in those fifteen years that marked my mother’s end of life, were crossing guards at every turning point who could say to us, “Let’s talk about how you want to live your future.”

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Photo credit: Todd Hochberg

April 16, 2010 is National Healthcare Decisions Day. Use it to motivate yourself to complete healthcare directives. Use it as a reason to hold educational events in your institutions. Use the resources at www.nhdd.org to help those who, like me, need someone like you to help navigate the rugged road at the end of life. By the way, The Chrysalis Room at the Fairmont Care Center in Chicago has become so successful that the Lancaster Corporation has made private rooms in four other facilities they own.