

Published in the *Pasadena Star-News* on March 29, 2020

Have that end-of-life conversation right now

What do you say when your dad tells you he doesn't want to live like this anymore? It's a moment I clearly recall even though it was almost twenty years ago. I can still see exhausted, emaciated Dad sitting in a plaid cotton robe in his Medicare lift chair. He wore big block sunglasses due to an eye condition that made his eyes jiggle like jumping beans.

Though his eyes were concealed, I heard the vulnerability and anguish in his voice. He was asking for help. I froze. Dad had been constantly sick for the past two years. He was almost blind and couldn't see the television or his computer screen. He couldn't do fix-it jobs around the house or work in the yard, activities that had kept him busy since he had retired. My parents had reluctantly sold their home and moved into a retirement community.

Then Dad got the diagnosis of non-Hodgkin's lymphoma with a terrible prognosis: four weeks to live, without treatment. The oncologist recommended radiation therapy. After the third week, Dad was too weak to take more radiation and was sent from the oncology clinic to the hospital in an ambulance.

When I think of the three grueling weeks of radiation that my father went through, I deeply regret that I didn't have the courage to help him when he told me he didn't want to live like this anymore. I had been Manager of the Health Insurance and Advocacy Program (HICAP) and knew the Medicare Hospice benefit well.

I should have told Dad how hospice provides comfort care for terminally ill people. I should have told him he could go home and live in peace for the time he had remaining. He might have chosen to have the radiation anyway, but at least he would have known the alternative. But he had always been an authority figure and I simply couldn't get the words out of my mouth.

When I was growing up Dad was the boss of Mom and all the kids and no one

questioned his authority. Family patterns are deeply entrenched and topics like death are pretty near impossible to discuss. How could I, his daughter, talk to him about the fact that he was dying and was headed for a painful death, probably in the ICU?

I called his physician, Dr. Archer, and asked him to help us talk to Dad. I told him my father was a straight talker and not to sugar coat it. He told my dad, in the most compassionate way, that he considered guys like him terminal. When Dr. Archer spoke those words, it felt like the world stopped revolving.

Dad was quiet. Dr. Archer waited for him to speak. Then Dad said that he'd had a good long life and was grateful. From that moment on, with the help of the hospice team, my sister and I took our father home and cared for him until he passed peacefully in his sleep, 29 days later. We made the best of those last days of his life and they were some of the most richly lived of his 80 years on earth.

As COVID19 spreads in California there are frail elderly people in nursing homes, or still living in their own homes, who have one or more chronic diseases, and perhaps painful injuries that are still healing. They may feel like my dad did, but they can't bring themselves to say it to their adult children.

Most people don't know anything about hospice care and if they do, they dismiss it as "giving up." If an honest, loving conversation doesn't take place, thousands of people will contract the virus and end up on a ventilator, more miserable than ever and unlikely to survive.

Go to [medicare.gov](https://www.medicare.gov) and put "hospice" in the search box. Most people are aware of Advance Directives but haven't gotten around to filling one out. You can download a form at the Attorney General's website oag.ca.gov. There is another type written in less legal, more narrative language called Five Wishes. You can download a form at [fivewishes.org](https://www.fivewishes.org). They are the same legally binding documents; they just use different styles.

Do it today.