

# Monrovia Living Magazine - March 2022

## Becoming the Adult Your Parent Needs

By Nan Kuhlman - Photos by Russell Hollinhurst

The subject of death is a difficult one. It's something we all will face but find it hard to discuss, especially with those who are close to us and especially in the context of serious health issues. Kathleen Vallee Stein, a former advocate for seniors through the California Department of Aging, found herself facing the difficult conversation about death when her father was diagnosed with non-Hodgkin's lymphoma and given four weeks to live without treatment.

"At the end of the third week of radiation, [Dad] was taken to the hospital by ambulance because he was too weak to take the treatment. His physician said Dad would need a stomach tube to continue treatment because he was unable to eat or drink due to the radiation," Stein says. Because of her professional experience, she knew about the Medicare Hospice Benefit and had often recommended it to seriously ill people.

However, when it was her own father who was dying, she struggled to find the words to talk to him about it. Stein, along with her mother and sister, knew that her dad did not want to live out his last days with a feeding tube. She reached out to her father's physician to help convey to her father the terminal diagnosis and the need for hospice care.

“When the doctor told Dad that guys like him were considered terminal, my stomach fell to the floor, and massive guilt washed over me. But when my father told the doctor that he had had a good, long life and was grateful, I was flooded with relief and gratitude to my father for having the courage to accept his imminent death. That moment transformed all of our lives,” Stein says. For Stein and her family, hospice care made the last twenty-nine days of her father’s life “some of the richest of his eighty years on earth.”

Stein, a Monrovia resident since 1997, chronicles her family’s journey through those last twenty-nine days of her father’s life in her memoir *Loving Choices, Peaceful Passing: Why My Family Chose Hospice*, available through her website at [valleevue.com](http://valleevue.com). She has spoken to groups about hospice, along with publishing opinion articles on the topic in the *Los Angeles Times*, *Christian Science Monitor*, and the *Pasadena Star-News*, to name a few.

If you find yourself in a similar situation, Stein has a few suggestions to help. The first step is to clarify with the physician that the patient is terminally ill. According to Stein, the physician must certify that the patient has six months or less to live to receive hospice care under Medicare. [Medicare.gov](http://Medicare.gov) provides information about hospice services, which provide support for the patient’s physical, psychological, social, and spiritual needs.

For example, the “Providers & Services” tab on the [Medicare.gov](http://Medicare.gov) website opens a menu where clicking on “Find Care Providers” allows you to obtain a list of hospice agencies alphabetically by zip code. Through those links, consumers can find out important details,

such as conditions treated, general information, and quality, before calling. Stein has compiled information about hospice from [Medicare.gov](https://www.Medicare.gov) and created a two-page Medicare and Hospice Overview that can be downloaded from her website [valleevue.com](https://valleevue.com).

Another suggestion is to have an Advance Health Care Directive in place to communicate a patient's wishes for end-of-life care and name a power-of-attorney for health care in the event the patient is incapable of making decisions. "Having a legal document that clearly describes what the patient wants is good, but end-of-life care can be fluid and the patient's wishes might change, so it is up to the family to keep close tabs on what their loved one is thinking and feeling," Stein suggests. Stein's website [valleevue.com](https://valleevue.com) offers more information about Advance Healthcare Directives, and she suggests obtaining the forms through the California State Office of the Attorney General at [oag.ca.gov](https://oag.ca.gov) or through the website [fivewishes.org](https://fivewishes.org).

Stein believes that conflicts among family members are almost always a factor to prepare for when a family member is terminally ill. "While everyone might sincerely believe that they have the patient's best interest at heart, they may have diametrically opposed views about what that would look like and how it is to be accomplished. When family members get caught up in promoting their point of view, they can forget to ask the patient what they want," she says. This is why having an Advance Health Care Directive is important. In Stein's situation, her sister Anne worked with her as a team, providing emotional support, especially when two of their siblings showed up for a deathbed visit after having been estranged from

their father for a decade. “Emotions run high with family members in this situation, and I suggest you find someone you trust to express grievances and sibling rivalry issues with privately. Keep it away from your terminally ill loved one,” Stein recommends.

Stein learned two important lessons in her role as a caregiver to her parents. “The first one was how monumentally difficult it is to choose hospice over curative care. If I had not been familiar with the Medicare Hospice Benefit, we probably would have followed [the physician’s] advice to keep giving Dad radiation, and he would have died within days,” she says.

Another important lesson was about role reversal: “When I looked at my frail, emaciated dad, I didn’t see the authority figure of my childhood who was the unchallenged boss of the family but a very ill man who was dying and needed my help. It is very hard to go against the grain with a parent, to step up and care for them and make decisions on their behalf.

I knew my parents would need help to care for Dad at home, and I provided it for them. Still, I was scared to death that they would yell at me - that’s how deep role reversal goes,” Stein says. She emphasizes that adult children must overcome their childhood role and become the adult their parent needs, not treating the parent as a child but as another adult who needs their help.

She shares one example illustrating the difficulties of role reversal: “On the day Dad came home from the hospital, I was very afraid they would be upset that I hired home health aides and ordered the prescription service. My parents were frugal people and didn’t like to ask others for help. They had relied on each other during their fifty-six-year marriage, and I was intruding on their turf.

Later that day, my husband called to see how Dad was doing, and when I heard my father say, ‘Kathy took care of everything, and I’m relaxing in my bed at home,’ those were the sweetest words I ever heard. He was grateful for my help.”

Stein’s book was written as an encouragement to other families that they can care for their terminally ill loved one at home with the help of the hospice team. While many other books have been written on the topic by professionals, Stein wanted to offer a layperson’s perspective: “I wanted to share the story of a family who, though quite ordinary and slightly dysfunctional, was able to rise to the occasion and give their loved one a great gift. I had a much deeper relationship with my dad in his last days and get great comfort in knowing that he passed in peace.”