Reason #28

Because requests for medical aid in dying are not a failure of hospice or palliative care, they are an opportunity to improve the end-of-life care experience.

To give you some idea of who my mother was, what follows is the short death notice my brother and I placed in the New York Times.

“A strong, independent, intelligent and stubborn lady, Helen died on December 4, just a few months shy of her 95th birthday. She intensely loved her family, deeply cared for her friends and found a new focus for her contempt after the (2016) presidential election. Generous to many, and consistently voting against her self-interest in order to benefit others less fortunate, she also clipped grocery store coupons with religious fervor. She held herself to high ethical standards, yet shamelessly took advantage of the generous return policy at Bed, Bath & Beyond. She demanded that her only memorial be a cocktail party in her honor. All in all, it is doubtful we shall ever see her like again.”

In accordance with her demand, we held a cocktail party to celebrate my mother’s life, which by most accounts could be described as nothing short of wonderful.

Unfortunately, the end of life had a prolonged and horrible ending. Even now, I am deeply troubled by her death. My mother and I had numerous conversations regarding her end of life. She continuously asked me when she felt it was her time, that I would provide her with the “magic cocktail” to ease her suffering. I listened, I promised and I failed her.

About a year prior, she had stopped treatment for diffuse large B cell lymphoma. This is typically an aggressive cancer, but to our great surprise, it was of all things, a broken hip that eventually felled her.

After surgery to repair her hip and a week or two of utterly fruitless attempts to get her to move on her own, it became clear that further treatment and rehabilitation for her fracture was no longer an effective option and in fact caused her pain. She was never going to recover.

In her last few days, rehabilitation facility staff continually violated or ignored her expressed wishes and the recommendations of hospice professionals.

Despite her explicitly indicated intention not to eat, she was regularly awakened and offered food, and on at least one occasion was repeatedly questioned about why she did not want to eat. With the patient to nurse ratio frequently well above what we were told it was, and often no attending physician available or willing to actually attend to my mother, she spent much of her final time in unrelenting and excruciating pain. The need for care and attention does not diminish on Saturday or Sunday, and it certainly does not diminish on Thanksgiving.

Medical aid in dying is one component of end-of-life care, not an alternative to palliative or hospice care. And we know from experience in other states that have the full range of options available, that authorization of medical aid in dying actually improves end-of-life care overall for everyone, not just those who choose it.

In authorized states, doctors report that since the laws were implemented, they have made a point of improving their knowledge of pain management, hospice and other end-of-life treatments. This, in turn, has improved the conversations between doctors and their patients, with providers noting an increased willingness from patients to discuss and consider hospice specifically, and more appropriate patient-centered-care decisions being made at the end of life.

Requests for medical aid in dying are not a failure of hospice or palliative care, they are an opportunity to improve the end-of-life care experience. They are an opportunity to honor the beliefs and preferences of each unique individual and ensure that they have the option to die with dignity when they decide that the pain and suffering from their terminal disease are too great to withstand.

To join our mission, email Amanda Cavanaugh at acavanaugh@compassionandchoices.org.