

Gratitude

Dear Reader,

Many of my clients know that my husband, Mark, passed away at the end of August following a lengthy illness. We had a long and very stable marriage, and moving forward without him here is difficult.

I am just getting back to work now, at the end of September. From time to time, I plan to share parts of the last “journey” that Mark and I undertook together—not only to tell our story, but also to inform you, the reader, about the good, the bad, and the ugly of navigating “the system,” and about finding compassion in the most unexpected places.

The experience of navigating Mark’s last illness for some six years—the last two of which were particularly difficult for him—may not have made me a better person, but it has certainly made me a more understanding advocate for clients and families facing similar circumstances.

For this note, however, I want to express my sincerest gratitude to the many medical professionals, caregivers, and the team at Care Dimensions Hospice who helped us and stood by us as we traveled through, and ultimately reached the end of, what I will call “the illness journey.”

The Doctors

Mark had so many doctors over those years that it would take a full, single-spaced page to name them all. I do want to specifically recognize Dr. David Shein of Personal Physicians Healthcare, who became Mark’s primary care physician toward the end.

Mark did not come to Dr. Shein in good health. He was already in very serious condition, and Dr. Shein did absolutely everything he could to help.

Dr. Shein seemed not to sleep. He spent time with Mark, with me, and with my son. My son is a physician himself, so I had the good fortune of having two doctors doing what they could to help—and then “translating” it all for me.

Most important, Dr. Shein was responsive to Mark and worked with us to understand and consider the best possible treatments for him. The emphasis was generally on quality of life at the end of life.

Mark had lost his voice, but he had not lost his intelligence. We all hoped there would be enough time to “fix” his vocal cords. Sadly, there was not.

Toward the end, Mark communicated by writing and whispering. Dr. Shein took the time to understand that this very debilitated man was still mentally competent—and probably very afraid.

For that, I was deeply grateful.

Hospice

Eventually, Mark needed hospice care. He agreed to hospice despite wanting very badly to return home.

I am grateful that he was able to spend as much time at home as he did, with a series of caregivers as his disease progressed. But ultimately, home was no longer possible given the complexity of his medical needs.

Following a hospital stay, Mark went to hospice. We chose Care Dimensions Hospice in Lincoln, Massachusetts.

It was an incredible experience for all of us.

My son and I stayed with Mark throughout. The facility itself was beautiful and thoughtfully equipped—even with the ability to take a patient outside into the gardens while still in bed.

But what struck me most was the people.

Everyone seemed to be on a mission to help. Frankly, I have never seen anything quite like it anywhere. The competence and compassion of everyone—from the doctors and nurses to the people who cleaned the rooms—were extraordinary.

There was one nurse in particular who would come into the room so quietly and gently that it reminded me of Carl Sandburg's poem:

"The fog comes in on little cat feet..."

That image has stayed with me.

There is much more to be grateful for, but this note is long enough.

While I am deeply sad to have lost Mark, I know that our family did what we could. And I am profoundly grateful to the people who helped us along the way.

I plan to share more of this experience from time to time. Perhaps some of what we learned will be useful to others who find themselves unexpectedly beginning their own "illness journey."

For now, though, I simply want to say thank you.

Sincerely,

Susana