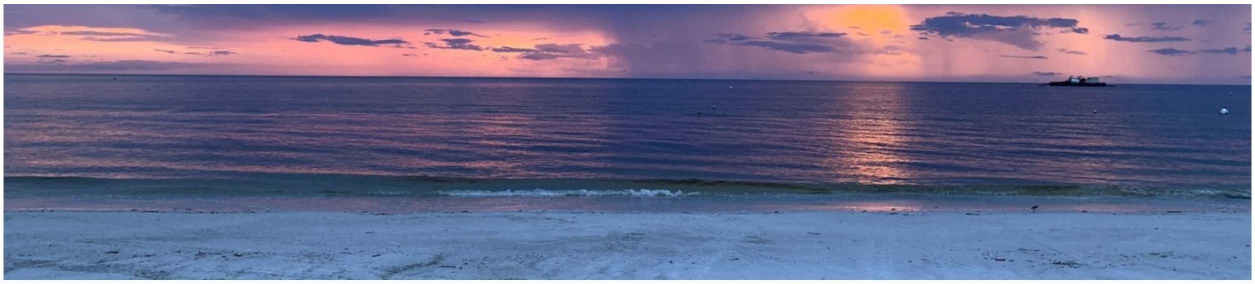

One Woman’s Story . . .

By Kate Washington

Ms. Washington is the author of a forthcoming book on caregiving, she has cared for her husband for six years through his treatment for lymphoma, a stem-cell transplant and chronic illness.

Five years ago, I stood in a tiny hospital room wondering how I was going to care for the man I loved most without succumbing to despair.

For four months, my husband, Brad, had been recovering from a stem-cell transplant that saved his life from aggressive lymphoma. The hospital administration said he must go home, but he needed a level of support that, I thought, only a hospital could provide.

His homecoming ought to have been cause for celebration. But I felt anything but joyful. The night before his discharge, unable to sleep, I felt so trapped and terrified that I called a suicide hotline, even though I wasn’t really sure I wanted to harm myself. I was so desperate I needed to hear a compassionate human voice, and I couldn’t think of anywhere else to turn.

I became painfully familiar with caregiving’s challenges during Brad’s months of chemo in 2015, but it was his 2016 stem-cell transplant — a last-ditch treatment for relapsed cancer. When he was discharged, he was immunocompromised, blind, too weak to walk unassisted, and unable to eat more than half his calories.

“He’ll need attendance 24 hours a day,” his oncologist told me. I stared, panic rising.

“How am I supposed to do that? We have two kids,” I said. Even meeting our family’s most basic needs would be impossible.

“Well, usually family steps in, and it works out fine,” the doctor replied, waving away my concerns. Our family had been extremely supportive but couldn’t drop everything indefinitely. A nurse suggested organizing shifts of friends, but my friends, like me, were working parents.

Besides, caring for Brad wasn't simply watching him. He came home with 35 medications that had to be administered on a mind-boggling schedule, as well as intravenous nutrition that I had to hook up, a complex procedure that I learned to perform in a hasty training session from a nurse. He needed blood sugar tests and assistance with toileting, showering and other intimate acts at which even close friends might well balk.

Insurance does not cover home attendants even when medically necessary. Our benefits did pay for skilled nursing visits and home health aides for assistance with showering twice a week, but for the 24-hour care the doctor prescribed, we had to pay out of pocket.

The summer after Brad came home, we spent more than $21,000 on in-home care, dipping into savings and an inheritance from my mother to do so. We were truly fortunate to have those resources; for many families, it would be out of reach.

Even though I had support systems and family to help, and we could afford supplemental care, my husband's long medical ordeal was almost unbearably stressful. Supporting a catastrophically ill person will never be easy, but it's far harder than it needs to be. The result for many is burnout, bankruptcy, and profound suffering. Plan ahead so you don't have to go through what I did.

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