

## We Can Offer You Some Resources

By Renata Louwers

Teetering on the cusp of widowhood at 45, I realized my intensity had sent the hospital social worker scurrying away. Ours had been a tense and circular conversation littered with euphemisms (by her) and rage (by me).

She had initiated the conversation by saying she understood how tough “the journey” had been. Then she continued on about the “discharge protocols.”

“I can’t take him home,” I protested. “I can’t care for him at home.”

As if to prove that I actually could care for him at home, she noted “the care team has already signed off” on his discharge, and she was just awaiting the paperwork. The team would, she assured me, do all they could to “support this transition.”

I told her that unless the team was coming home with us, I could not care for him at home.

“A hospital nurse will follow up in the morning by phone,” she said. “And the hospice nurse will visit daily.”

“Phone calls and a daily visit aren’t enough,” I said, struggling to contain my anger. “We already tried at-home hospice and that’s why we are here. He is bedbound with a catheter, groggy, in pain, and running fevers. How do I give him pills? How do I give him water? And why is it my job to learn how to manage a catheter?”

A woman in royal blue scrubs arrived and handed the social worker several loose papers.

“The paperwork just came through,” the social worker said.

Through many hospitalizations of family members, I had never witnessed a speedy discharge. Yet the one time I opposed the discharge, the bureaucracy buzzed with efficiency. I recognized the social worker meant well, but I lacked both the stamina and skill to care for my husband at home. She bore the brunt of my exasperation.

My husband suffered from sepsis as well as metastatic bladder cancer that had been advancing for a year. If he didn’t receive precise pain management, his pain escalated to intolerable levels. As his sole caregiver—his family lived halfway around the world—it all fell to me.

Would a doctor in the hospital ever recommend a bedbound and groggy patient try to swallow Tylenol or liquid morphine while lying down? No, because of the risk the patient might aspirate. But they were willing to send a caregiver-wife home to muddle through.

My conversation with the social worker ended when she inadvertently revealed the real reason for the speedy discharge.

“We need the bed,” she said.

I stared at her. I interpreted her statement to mean they needed the bed for someone they could fix.

“We’re not leaving because I can’t care for him at home by myself,” I repeated. “A nurse visiting once a day is not enough.”

The “care team” had visited me earlier to explain to me they did not believe they could do anything else to help him. They had spoken to me as if I did not understand or recognize this.

It was clear to me my husband was dying. It was not clear to me how I was supposed to care for him until he did.

And no one at the hospital had offered practical help for that problem.

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Previous social workers—during previous hospital stays—had handed me lists of home health agencies with titles like “Helpful Resources.”

Buying your way out of a problem is always an option. And buy it—to the extent we could—we did. For \$25 an hour, a home health aide with a few weeks of “training” would show up and help us out periodically.

But here’s a major problem with home-health care: a caregiver often needs significant help at specific times of day for specific tasks. These tasks might total two hours over the course of a morning and afternoon. But home health agencies typically require a minimum purchase of a four-hour shift. This makes sense from the agency’s perspective. But a family buying the care often ends up paying for hours of help it doesn’t need.

My needs typically focused on getting my groggy husband out of bed and dressed in the morning. I first had to persuade him to take Tylenol to quell the fever with which he usually woke. Then a few hours later, I often needed help getting him into the car (from our high-rise condominium) to get to a doctor’s appointment.

So even if I needed help only at 8 a.m. and then again at 1 p.m., I had to buy eight hours of care. Twenty-five dollars, times eight hours, times seven days a week totaled \$1,400 a week.

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In the quiet after the social worker left, I cried as I stared down at the hospital’s speckled linoleum. During the prior year, we had ricocheted from crisis to crisis. The Ivy-League-educated doctors could not fix him. I had raged in waiting rooms about the oncology flyers touting early detection. His bladder cancer *had* been detected early, before it spread. It had been treated. He had been deemed “cured.” And then two years later it had returned as metastatic.

Even as a well-insured, upper-middle-class couple in a progressive American city, we could not afford to fully buy our way out of our home-health problem. Nor could we navigate the healthcare system without frustration. What must this be like for those less privileged?

My rage felt bottomless regarding the platitudes—the feigned empathy, the references to “the journey”— from one too many nurses. Sometimes I raged in solitude; sometimes I raged

to their faces. I knew I viewed them unfairly sometimes. But it felt like the larger medical system kept creating infuriating obstacles. And that kept me stuck in rage.

I found solace during that year in a writing group for cancer patients and caregivers. Offered twice a month at a major university cancer center, I found it to be the only place where I could express the raw and painful reality of my life. And I did not feel compelled to offer a trigger warning (as I so often did in other settings).

A woman—a social worker, writer, and cancer survivor—led the group in writing prompts. University budget cuts loomed constantly as a threat to the group’s continued existence.

Most of my writing detailed frustrations with the medical and insurance systems. Sometimes I found dark humor in our circumstances—such as doctors advising that my husband was “too sick” to do certain things. They never seemed to catch the irony of telling someone they had already deemed “terminal” that he was “too sick” to do something. What, exactly, was the worst-case scenario? Hadn’t we already been handed that?

Advanced cancer caregiving is a lonely venture. Especially at an age when friends are raising kids, not caring for dying spouses. I enrolled in an online class that focused on the work of Louise DeSalvo and writing as a means for healing trauma. I wrote and wrote and wondered why the world at large failed to give voice to the many challenges we encountered.

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An hour or so after the first hospital social worker left, a different one appeared accompanied by a doctor I had never met. They said they had been “brainstorming a solution.” They said my husband could be transferred to the Zen Hospice Project and cared for at a reasonable price.

I had heard of San Francisco’s Zen Hospice Project but knew little about it. Although the new social worker had already lined up transportation for my husband, I insisted on visiting before transferring him.

Thirty minutes later, I crossed the threshold into the serenity of what felt like a Victorian bed and breakfast in San Francisco’s Hayes Valley. Fresh flowers splayed across the mouth of a giant vase near the front door. The curved staircase, with its intricately carved wooden banister, hearkened back to the 19<sup>th</sup> century. The sunlight through the bay window created shifting parallelograms on the wood floor. I knew this was the place.

The not-yet-nationally-known Dr. BJ Miller sat with me a few days later as I struggled with my husband’s original wishes to “do everything.” He offered to make the tough call for me regarding a DNR order; he explained that California law allowed a doctor to decide on my behalf. His compassion, and the relief it gave me, felt like an alternate universe compared to the medical system in which we had been mired over the prior year.

Each time I arrived at the Guest House (as it was called), a volunteer asked what she could make me for lunch. Homemade soups and cookies and flavorful sandwiches flowed from that kitchen. I regained the appetite I had lost months earlier. The volunteers told me I could finally be a wife instead of a caregiver.

My husband died at the Guest House after two weeks there, in late April 2014. Witnessing the serenity of his time there, my octogenarian mother asked—only half joking— if was possible to make an advance reservation at the Guest House.

A few years after my husband's death, the Guest House and my cancer-writing group both also died from complications specific to their circumstances.

Seven years later, I still wonder why the compassion we experienced at the Guest House felt so uncommon in a system that claims its highest priority is providing care.

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