intima
a journal of narrative medicine

FIELD NOTES | SPRING 2017

Not in Our Bed

By Giamila Fantuzzi

He did not want to go home, did not want to die at home. My husband's cancer had run its course, he knew he would die soon and was ready for it. He just did not want to do it in our bed.

We had started hospice care ten days earlier, hoping to stop the frantic runs to the emergency room that had punctuated the last couple of months: a mini-stroke, the swelling of an arm and hand due to clotting problems, an opioid-induced bowel obstruction. Yet here we were, in the emergency room once again, this time due to a badly placed catheter that lead to major bleeding and pain. The staff solved the immediate problem, but this time S. did not want to return home. He had had enough. Enough emergencies, enough anxiety about the emergencies, enough worry about putting too much responsibility on my shoulders. Most of all, home meant life to him and by now all he wanted was to be free to die. He needed to detach himself from his books and paintings, from the kitchen we had just painted golden yellow, where he had prepared magnificent dinners for our many friends. We had loved and laughed so much in that place. He needed to let go of all of that.

Together, we convinced the doctor in the emergency room to admit S. to the hospital. He spent the night there before they tried to convince him to return home. "You have a comfortable apartment, a wonderful wife, friends that will visit, nurses that will attend to your needs. Your things, your memories, your life will surround you. Why would you not want to be there?" The answer was simple, though it appeared to take the medical personnel by surprise: S. did not want to return home because he needed to unfasten from his life before he could feel emotionally, not only rationally, ready to die.

I guess we were persuasive, and a bed came up in one of the few inpatient hospices in Chicago. That place was amazing, something I would call a Godsend if I believed in God. Nurses, aids, social workers, chaplains, palliative care physicians: everybody made us feel as if our well-being was the only thing that mattered. Just as important was the fact that S. was now in a neutral, caring environment where he could finally let go. I saw him relax, all the tension and apprehension washing away from his face.

Statistics show that 80% of Americans would prefer to die in the warmth of their own shelter, though less than half end up being able to do so. Delayed entry into hospice care and hopeless attempts to rescue what cannot be rescued help explain this discrepancy. However, as much as they bring solace to most, familiar surroundings create stress and discomfort for a sizeable minority of the population. Hospitals and nursing homes are the wrong answer for both those

who do and those who do not want to die at home. There is a need for alternative spaces and for open minds. As Nitin K. Ahujia wrote in his article *An Apology for the Institutionalized Death*, "Life is pleasant, dying is weird—why should it pain us to have them separated, as far as they can go?"

We were privileged to find a place where my husband could die the way he wanted. But, as S. never tired of saying, one should never have to turn to the word privilege for something that's meant to be a basic human right: the freedom not only to live, but also to die, according to one's choices.

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