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Broken promises, love and long nights

Melissa Musick Nussbaum | Jun. 8, 2011 My Table Is Spread

Sometime in the last two months, my mother stopped sleeping at night. The hospice nurses called it ?sundowning.? My sister-in-law, who had just moved her father into a locked memory care unit, called it ?dementia?s 36-hour day.?

Imagine a 100-pound newborn, her days and nights mixed up. Now imagine that the newborn has osteoarthritis and the faint beginnings of pressure sores along her protruding spine and skin the thickness and strength of moistened tissue paper. This is a baby who can neither be swaddled nor soothed.

My mother began pacing the long hours of the night, taking her clothes out of the drawers and piling them on the floor, checking and rechecking for the items she was sure I had stolen. She picked up blankets, looking at them curiously, not understanding where they had come from or whose they were. What she missed, she did not have; what she had, she did not recognize. She was anxious and confused.

?Why are those men here?? I told her there were no men. Later, worn down by her frail mania, I would tell her I didn?t know what the men wanted. Both statements were true.

We hired night caregivers, four kind women working as a team, spelling one another, and spelling me. Three of the caregivers are members of a small holiness church whose ministries include care for the elderly and the ill. One of the caregivers is a nursing student at the local state university. The nursing student is just 19. She is working her way through school.

When the young helper called sobbing one Monday morning at three, I thought she was calling to tell me my mother had died or, perhaps worse, fallen. She called to tell me my mother would not sleep, would not stay in bed or in her chair, would not keep the oxygen tube in her nose. I got up and went through the darkness to where my mother stood riffling through her closet while her helper stood by, crying and saying, ?I?m sorry. I?m so sorry. I don?t know what to do.?

Me neither.

I sent the young woman home to get some sleep before her nine o?clock class. I started, again, the story of how I had not taken my mother?s white pants.

I recall a night just after my fourth child was born. She would not sleep, unless I was walking with her or rocking her or feeding her. If I bent to put her down in the bassinet, she startled and began to wail.

I remember watching the clock, knowing how soon my other three children would be awake and ready to be fed and dressed. At some point my lullabies turned into a single tearful refrain, ?Please go to sleep.?

Twenty-seven years ago, I had no idea how manageable that infant and her sorrows would someday seem.

The hospice nurses tried giving my mother a chip of an Ativan tablet at bedtime. Then they added a dollop of an antipsychotic. Then more Ativan. My mother?s hallucinations lifted a bit but still she could not sleep.

One of the holiness ladies brought in her laptop and set it up so that mother could watch a real-time video of an eagle in Iowa sitting on her nest, keeping the eggs beneath her warm and safe. There was no music or narration, just the sounds of the wind and the eagle as she ruffled her feathers to resettle on the nest. Sometimes the eagle and her mate called to one another. I quieted as I watched, but my mother could not stop her pacing to imitate the placid raptor.

All of the caregivers had day jobs. My mother alone, like an infant, could sleep on her schedule, a schedule only her body could recognize as in some way ordered.

We kept looking for a nursing home that did not resemble an electronics superstore, with the residents parked in front of the giant screens that everywhere greeted us, in the lobbies, in the dining rooms, in the lounges, in the game rooms, in the residents? rooms.

We made a pact, my husband and I. The Golden Rule would be the guide. If either one of us could see putting the other in a place, it stayed on the list.

Well ... the Golden Rule and a hefty amount of cash. Doing unto others as you would have them do unto to you in the assisted-living world is much easier for those who share my mother?s lucky trifecta: Medicare, veteran?s benefits and savings.

Then we found it, a well-lit, quiet complex, with exercise classes, an attentive staff and big windows looking out on the mountains. This place offers restaurant-style dining, lectures, concerts and an indoor saline pool. There are scenic drives, lunches out and shopping days. The televisions are dark and silent, except for special shows when the staff tunes in the recent royal wedding or a weekly ?I Love Lucy? fest.

But when Mother was evaluated by a nurse practitioner on staff, the recommendation came back that she should be in the memory care unit. This unit is locked, the door is alarmed, and the windows, though also large and looking out on the mountains, do not open. One woman there goes to the windows each day, looking out on the mountains of Colorado and seeing the prairies of Minnesota. Another man watches the garden for signs of a storm. He shuffles to the door, watching and worrying about the ceramic gnomes, the ?little people,? he calls them, who get wet when it rains. Others have returned to that time of infancy when sleep comes suddenly and with authority, claiming most of the hours. Some do not speak at all.

Some are more social and verbal than my mother but the not sleeping at night, the sundowning, the 36-hour day, these they hold in terrible common. The number of staffers increases at night.

On Holy Saturday, when I would have usually been in the kitchen glazing the double chocolate cheesecake and marinating the roast, I helped move my mother out of the home where I had prayed she would live to the end of her days.

?Please, take me home,? she begs each time I visit her. ?Please,? she cries. ?I won?t be in your way. I?ll do whatever you say. I promise. Please, oh, please, let me go home.?

I wish I could pretend she means heaven when she says home but she means my house, where I did, indeed, tell her she could live out her days. I made a promise, and I broke it. How many other times, she must wonder, have I lied?

My cousin went to visit her. She says Mother thought she was Dorothy Jo, a childhood friend, now long dead. Mother told ?Dorothy Jo? why she had been forbidden to play with her. It?s because Dorothy Jo?s mother was having a, a -- she stops, searching for the word -- ?a, a, a, you know, a screwball with the doctor.?

My mother says, ?I know you hated me.? My cousin hugs her and says, ?Betty, I love you. And I forgive you.?

Sometimes my mother?s grief turns to anger. ?Aren?t you sorry?? she demands of me. ?Aren?t you sorry you don?t have me??

?Yes,? I tell her, weeping. ?Yes, I am. I am so sorry.?

Perhaps one of these days, on one of these visits, my mother will be Dorothy Jo, an innocent punished for the sins of another. Perhaps then my mother can hug me, and say, ?I love you, Melissa. And I forgive you.?

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