

Virtual Mentor

American Medical Association Journal of Ethics
April 2002, Volume 4, Number 4: 116-119.

PERSONAL NARRATIVE

Through the Caregiver's Eyes: Flowers on the Window Sill, First Day as a Hospice Volunteer

Diedre Martin

The nurse's station and hallway are empty. Within a few minutes, I hear voices, and then see a nurse and 2 other people exit one of the rooms. I recognize the nurse, Sara, who was introduced to me at orientation a few weeks ago. Luckily, she remembers me and waves a friendly hello.

After a quick but warm welcome, she introduces me to volunteers Kathy and Paul. Both have worked here for a couple of years. They spent this morning helping Sara with patient baths, and only now do they have time to catch up with other chores. Twenty minutes ago, someone from Food Services delivered a large silver cart that houses each patient's lunch and keeps them warm until a volunteer or aide has time to deliver the trays of food to the few who still eat.

Kathy and Paul begin serving the lunches. As Kathy takes out the first tray, I ask her about the soft sounds of nature I hear coming from one of the rooms. The meditative recordings of a waterfall, ocean, and the songs of birds, she explains, are from a tape. The daughter of a comatose patient hopes the sounds comfort him during those times no one from the family can be with him.

Kathy starts down the hall, carrying one of the lunch trays. Left standing alone, I hesitate, wondering if I should find Sara or wait until she looks for me. Moments later, Sara steps out from one of the rooms and beckons to me. She asks if I will spend time with an elderly patient, Mrs. Gruber, who is depressed. Sara hopes a visitor might cheer her. The woman suffers from a severe heart ailment; but, because death does not seem imminent and her pain has been brought under control, her insurance company has insisted that she leave hospice. Later today, she will be transferred to a nursing home.

Mrs. Gruber is furious over the insurance company's mandate and at the medical staff who must enforce it. No matter how often the nurse, doctor, or social worker explains why she must leave, she feels as though she is being "unjustly kicked out of hospice." Her battle lost, she has sunk into a deep depression. Unless absolutely necessary, she refuses to speak to any staff member. Sara finishes the sketch of Mrs. Gruber's problems and returns to her duties, leaving me to take on my first hospice assignment.

Mrs. Gruber sits in a lounge chair, staring down at the breakfast tray that was delivered about 7:00 this morning. On the tray several plates are filled with food. She won't allow anyone to remove the tray, claiming she is "still working on it." A large off-white plate displays two link sausages and a yellow patch of scrambled eggs that seem frozen in position. On a separate plate, toast forms a perfect stack of light-brown triangles. From the slight streaks on her glass, I think she might have sipped a little of her orange juice. The tea bag lies unopened, and by now, the small pot of water is surely at room temperature.

Shoulders curved and head bent forward so her chin almost rests on her chest, Mrs. Gruber barely looks at me when I enter the room. She continues to stare at her untouched food. I introduce myself and am gratified with a slight nod of acknowledgment. But then I stand uncomfortably in silence.

The only guest chair is inaccessible. The large chair she occupies is positioned at the foot of the bed. Wedged tightly between the chair and bed is the tray table, leaving no room for me to slip between them. Her indifference makes me reluctant to ask her to stand up so I can move the table out of the way. My only recourse is to climb over the bed, which I don't want to do unless she gives her permission. When I ask if it is okay to do so, she doesn't respond. At this point, more than anything, I just want to leave. I feel I am intruding upon her privacy, yet I wonder if there isn't some way I can help her.

I decide to make light of my situation. Adopting a joking tone, I announce my intention to climb over her bed but request that she not "snitch on me." She glances at me but says nothing. I bend down and look directly into her eyes, "Do you mind if I crawl over your bed to get to the chair?" No reaction. "Promise you won't tell on me?" With a slight nod to her head, she rewards me with a barely visible smile.

Once settled into a chair, I take notice of her appearance. Mrs. Gruber is an attractive woman in her late seventies. Her silver-gray hair forms natural, gentle waves that are brushed back from her face. Blue veins stand out in contrast to her translucent white skin. Her expression is slack, devoid of animation. I prod her with questions about her life and family, but the answers are flat even when we talk about her children and grandchildren.

"Are you married?"

She responds, simply and without emotion, "My husband died a year ago." There is a pause, "I took care of him. He was sick for a long time before he died." Then she is silent.

Believing there must be a topic that will catch her interest, I keep trying. "Are you a good cook?"

"I am an adequate cook."

"Do you cook any ethnic dishes?"

"I cook regular American food, nothing special."

I wonder when I should give up. An uninvited guest, what right have I to impose myself on her and ask these questions about her life? Am I not invading her privacy, trampling on her prerogative to be alone? I want to escape from her and the uneasy feeling that I have no business being in her room.

I try again, asking if she had worked outside the home. I learn that she was the cook in the same household where her husband worked as chauffeur. No answer does she linger over. I glean nothing about the person behind the answers—until I ask about the multitude of perfect African violets that crowd the room's window sill in pots large and small.

It is remarkable to watch Mrs. Gruber's transformation. She raises her head, looks at her velvety flowers of purple, pink, and white and then at me. Her face alters and reflects interest, and she begins to speak in longer sentences. She describes each type of violet and why it is special. Her voice becomes kind when speaking of them. It is as though she were speaking of beloved grandchildren.

"I love these flowers. People ask me for cuttings, but I never give them to anyone unless I know they will be properly cared for." Only then are they rewarded with cuttings. She encourages me to learn how to care for these "magnificent plants," and I listen intently to her enthusiastic lecture.

While talking about the flowers, she interrupts the flow of words to express how disappointed she is in everyone. Her agitation grows as she describes the injustice of the decision to put her in a nursing home. Most people, I remind her, want to leave hospice and a reassignment such as hers would be seen as an encouraging sign. But Mrs. Gruber reminds me of where she is going—a nursing home—and she dreads it. Her feelings about leaving are direct: "I would rather die than go into the nursing home."

I am reminded of my grandmother Dora. Widowed in her mid-forties, she lived with us. One of the earliest serious discussions I had with my grandmother concerned the nursing home. When she was in a bad mood, she would comment upon her fears of being sent away to it. As a little girl who loved her grandmother and saw her as an integral part of the family, I could not understand the fears she expressed. Besides, I saw my grandmother as young and healthy. I had a vague understanding that the nursing home was for old and sick people. It didn't matter what I thought. My grandmother feared it just like Mrs. Gruber does now.

Thoughts of my grandmother renew my desire to help Mrs. Gruber, but she shows no interest in my attempts and finds nothing compelling in my arguments. Leaving hospice for the nursing home is worse than a death sentence to her, and she views

the continuation of her life with indifference. The joy she exhibited while speaking of her violets is gone. If she ever felt enthusiasm for life, it had been spent long ago.

I offer to help her back to bed, but she refuses. I climb back over her bed and leave, carrying the breakfast tray cluttered with uneaten food.

As I drive home late in the afternoon, I wonder if this is the type of community service I want to do. I am afraid what I see in hospice will depress me and affect my mood at home. I decide I will commit to the work for 6 months, and then reevaluate my decision. One thing I am sure of: No matter how briefly I choose to do this type of work, it will be challenging.

Death plucks my ear and says,
"Live - I am coming."
(Virgil, 70-19 B.C.)

Diedre Martin lives with her two daughters in Milwaukee where she writes and works with members of a documentary film company.

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2002 American Medical Association. All rights reserved.