

# Virtual Mentor

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## Medical humanities

### An evening on the hospice unit

by Allison Grady

Nervous anticipation always swirls in the depths of my stomach when I hear the familiar “ding” of the elevator signaling that I have reached the top floor of the hospital. Some of the staff have said that hospice is put on the top level because you’re the closest to heaven, but, whatever the reason, riding past those other floors always gives me time to imagine what I will find once the double doors open.

As I walk out of the elevators I am most struck by the relative silence. There are no beeping machines, no broadcast pages, no nurses frantically running in and out of rooms. Instead there are six patient rooms, and all but one are exclusively for single occupancy. In addition to patient rooms the hospice unit has a family room complete with games, cable television and VCR, pamphlets about various diseases and about grief, and two telephones that allow the visitors to connect with those who are unable to pace the hospital halls worrying about a loved one. Adjoining the family room is a kitchen for family and friends. Several other rooms that are used less frequently fill the remainder of the floor. The French doors I walk through welcome me to the unit; to the left and right offices are discreetly tucked into corners.

Although there are no “visitor’s hours” on this unit—it never closes—the soft classical music I have to strain to hear gives the impression that no one has disturbed this area of the hospital in hours. I hustle by the large conference room, the supply room and the quiet room where private phone calls can be placed. Halfway down the hall, I cross an artificial threshold and enter into a more intimate portion of the unit. I see the first patient room and notice that, while the curtain is drawn shielding the identity of the patient, the heavy oak door is still open. It’s not until now that I smell the mass-produced meatloaf—Wednesday night’s dinner—and see the two nurses on-duty—Christine and Abby—charting notes at the cluttered work station to my left.

Christine, Abby and I exchange warm greetings as I slip behind the nurses station and into the small “report room” where I store my purse. As I put on my teal volunteer jacket I survey the walls for new cards from families of former patients thanking us for our care and concern during their loved one’s last days. I notice the card from Mr. Cutler’s family—a picture of a bird soaring into the sunset—and remember my interactions with him—the two baths I gave him, talking with his children and the drawings by his young grandchildren that papered his walls. But the

time for sustained remembrance is short—the patient census board hanging on the wall shows that we are full.

There are six patients on the unit. As I look at the volunteer report sheets that list the patient name, age, diagnosis, abbreviated psychosocial status, presence of family members or special friends, and any special instructions such as an indication that the patient should receive “nothing by mouth” (also known as NPO), Abby enters the report room and asks if I’m ready for the daily report. As I reach for a pen she launches into a more detailed explanation of the volunteer report sheet. “Mr. Nathan in 703 is very anxious—someone needs to check on him every ten minutes or so just to be sure that he’s not trying to get out of bed. He’s not able to communicate very well; the Alzheimer’s has really eroded his ability to speak, but he listens and is cooperative. Sometimes he likes people to read to him, so you can see if he’s in the mood for that.

Now, Mr. Geragos in 705 has a lot of family here. He’s not doing so well—probably hours to *maybe* a day but I wouldn’t be surprised if it happened tonight. Anyway, there are a lot of people here visiting including his wife, Judy, his two sons, and his three brothers. The two sons are about your age...” Abby continues to talk to me about Mr. Geragos, but for a split second I am jolted by her noting that Mr. Geragos’s children are my age. It is always jarring for me to hear that my peers are experiencing a loss that I have been fortunate enough to have evaded for so long. Snapping back to the present moment, I listen to the rest of Abby’s report.

It is the patients who teeter between this world and the next whose family members tend to be the most receptive to my help and compassion. As a volunteer I am not here to pity the family or to gawk at the patient, but rather to offer whatever objective support I can. Sometimes that means that I will make the visitors a dinner of soup or a baked good; other times I just talk to family and friends about their loved one. It is always fascinating to hear stories about the lives people have led and to be reminded that, no matter how globe-trotting or parochial one’s life has been, the fact remains that for most of us death will be a simple and humbling ending. For patients who have no family members present, volunteers strive to make dying as comfortable as possible by holding a hand, tidying up the room or providing basic personal care.

Armed with information and ready to take on the evening I first stop by each room and talk to family members and patients. I ask if I can bring them anything: water, coffee, a newspaper? Although most refuse, I like to use this time as a way of introducing myself and letting them know that if they need anything I’m happy to get it or locate the person who can. Moving to the kitchen, I throw away old food, make fresh coffee and wrap up and refrigerate any dinner trays that were not delivered to patients or eaten by their families. Finally I put a load of laundry into the washing machine. On this unit patients are encouraged to bring their old night gowns and pillow cases with them as reminders of home, and we have the ability to wash them separately from the hospital-issued linens. Once the housekeeping tasks are

complete, I'm ready to dive into my other favorite aspect of the volunteer experience: patient care.

### **Personal care**

“Alli, can you get supplies ready for a bath for 701?” Abby asks. For some, referring to a patient by a room number seems impersonal, but confidentiality dictates that patient names should be protected in a public setting, so I glance at the report sheet to find out who Abby is referring to. Eagerly I gather the night gown and warm the moist wipes that we will use to wash Mrs. Kramer, find a fresh set of sheets and padding to be placed under her, and grab an adult-sized diaper to replace the one she is wearing.

As I enter the room with Abby, I introduce myself to Mrs. Kramer, who is chipper and alert. We explain that we're going to give her a bath and change her sheets and she seems agreeable to this pampering. Abby begins with her face and I with her feet; we use the warm wipes to wash her literally from head to toe. Mrs. Kramer's feet are dry and her toenails are hard but brittle. She is clearly self-conscious of this as she implores me not to look at them, but I assure her that I'm only here to clean, not to judge. As I move onto her legs, I can't help but notice that they are essentially bone covered by a thin layer of discolored skin—mostly from the months of radiation and cancer treatments along with age—but she enjoys my rubbing. She explains that these baths are the only human touch that she has had in months that did not involve invasive poking and prodding and for that she is grateful. After spreading some lotion on Mrs. Kramer's lower extremities, Abby and I meet in the middle of her body. We untie her nightgown and remove her arms from the oversize sleeves and wash her chest. I lift up each sagging breast—“a little modesty dear,” Mrs. Kramer chides—and I wash under and between them before covering her up again. Abby unpeels Mrs. Kramer's diaper, washes her front “privates” and checks to be sure that the catheter is in place.

Carefully we roll Mrs. Kramer onto one side and I wash her back. Like her legs, her back is bony and dry. I spread more lotion on her and I can feel her body relax. Abby and I fully remove the diaper, and the odor instantly forces me to breathe through my mouth. I'm used to this smell by now—feces, light sweat and sickness—sometimes worse than others; luckily this is not one of the worst. Embarrassed by her inability to care for herself, she apologizes and I do my best to assure her that this is not a problem at all and that we just want her to be as comfortable as possible. “But,” she says, her voice trailing away from me, “I feel badly. You'd think that with all of these tests and hospital stays I'd be used to it. But cleaning yourself is something that you almost take for granted after 76 years.” By the time she is done apologizing and explaining, I am done washing and have started to remove her old sheets and put on the new ones. Making a bed with someone lying in it is a unique skill, and based on my efficient tucking, pushing and arranging of the sheet, pad and diaper, I'd say that I'm becoming quite an expert.

Abby and I gently roll Mrs. Kramer over to the other side of the bed where Abby secures the new diaper, ties the nightgown and attaches the sheets onto that side of the bed. As Abby gently lifts Mrs. Kramer's head and shoulders, I slip in two freshly cased pillows and, once her head is positioned, we comb her coarse gray hair and ask her about the people who came to visit her today. Our final act with Mrs. Kramer is moving her up higher on the bed and this pull upwards is like a little ride for her. We stuff some pillows at the foot of the bed to prevent her feet from getting blisters, place a small homemade pillow under her slightly bent arm and another one behind her back to help ward off bed sores. Mrs. Kramer is grateful but exhausted after this half hour of activity and, as we pitch the dirty linens into the cart and wrap up the garbage, we notice that she is already sleeping lightly. We turn off the main lights and quietly exit the room.

### **The moment of death**

When Abby and I emerge from Mrs. Kramer's room, we are struck by the relatively few people left mingling in the hall. It appears that most of Mr. Geragos's family have decided to go home for the night. All that remain are his wife and their two sons, and even they are preparing to leave. Mr. Geragos's wife, Judy, stands sullenly in the hallway, her eyes bloodshot and her nose raw. I can overhear Christine speaking with her, "Well, it could be anytime now. We just never know. But there is nothing wrong with going home and getting some sleep. You have to take care of you, too. We can call you as soon as anything changes..." I continue walking by and do not hear Judy's response, but infer that Christine's plan is acceptable because she puts on her jacket and heads for the dimly lit exit with her two silent children. "We'll call you as soon as he makes any changes or if things look imminent. But you have to know it can be any time now." Christine opens her arms to embrace Judy and they hug for a few seconds.

"I know this could be the last time I see him, but there is nothing more I can do. We've all said our goodbyes. Promise me you'll call as soon as anything changes. My cell phone is dead," Judy says looking at its blank screen, "but we'll be home in about 45 minutes." Christine and Judy continue to talk and I walk over to the nurses station where I catch up with my co-volunteer, Patti, for the first time all evening.

Once Judy leaves, Patti and I enter Mr. Geragos's room. His breathing is labored. His skin appears to be naturally olive, but now there is a tint of yellow to it. His large brown eyes are open but vacant and he takes big gasping breaths like he would take if he were drowning. Patti talks quietly to Mr. Geragos—it is said that hearing is usually the last of the senses to go—while I hold his hand and stroke his head. Twenty minutes pass and Mr. Geragos continues to grasp at life, but now the gasps are less frequent and more shallow. Patti tiptoes out of the room to let Christine know of Mr. Geragos's deteriorating condition, and Christine leaves a message on Judy's home answering machine as she promised.

Back in the room, I've begun talking to him while still holding his hand and stroking his head. When you don't know someone it almost feels like an intrusion to talk to

them as they straddle life and death. Sometimes words fail, and I find myself saying a silent prayer or just thinking intensely about the patient who is before me. Who was this person? What was he like? So many questions race through my mind. Working on this unit, you learn that silence, sometimes, is the best way of communicating.

When Patti re-enters, I let her take up the talking again, but she too, is realizing that this might be a moment when words are unnecessary. We exchange looks but do not say anything—we both know what is coming. The minutes tick by and the breathing becomes more spacious, the gasps, while still forceful, are now more shallow. Suddenly, the only sound is the classical music playing overhead. Patti counts in her head—I know this because I am doing it too—one, two, three, four, five—and then Mr. Geragos breathes again. I'm not sure why I count, but it helps me to get an idea of how far apart each breath is and I am able to compare it to the last. I tighten my grip on his hand, but it already feels lifeless. He does not squeeze back and it seems his eyes are further up in his head. Again, the sounds of the building strings and the booming percussion fill my ears and I restart my silent count—one, two, three, four, five, six—another breath. My mind cannot help but wonder if he is aware of his own struggles to breathe or if he is already in that next place. Nothing suggests that he is in any pain. I know that he was medicated earlier in the day, and he has not shown any signs of discomfort or pain since.

Patti begins talking again, quieter this time, and I rub his arms and shoulders giving his hand a rest. One, two, three, four, five, six, seven, eight, nine, ten—nothing. Patti and I wait, but we do not hear a sound. Time seems to have stood still. She reaches to touch him and—*breath*. We are both startled by it, but we are undaunted. We are committed to staying gathered at his bed until there is no reason to be there anymore. It's after eight and we both know that our scheduled volunteer time is up, but neither of us will leave this man here alone as long as he is alive. There is another silence—this time even the music is between movements—and I look skeptically at Patti. . . .ten, eleven, twelve, thirteen, fourteen, fifteen. Still nothing. We reach out to touch him just under his chin, but there is no reaction. Mr. Geragos seems more relaxed and we can only hope at peace. I move his hand closer to his side. Still nothing. We stand at his bedside and we both bow our heads. We wait a minute longer—could this be the time when he will breathe again—but we know from his posture and the eerie silence, no, not this time.

Patti goes to tell Christine that Mr. Geragos has died, and I walk out of the room, while taking one last look, and go to get my purse from the report room. I prepare to walk down that hall for the final time until next week and I feel satisfied with the work I have done. It is getting late and another day of non-hospice-related work awaits me in the morning. As I shuffle down the hall I can hear Christine saying, “No, no, Judy, two volunteers were with him. . . .Yes, the whole time. You can be sure that he wasn't alone.”

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