

Do NOT Resuscitate

A well-orchestrated plan for death ends on a brutal note.

BY DAVID MULLER

LIKE MANY HEALTH CARE PROVIDERS, I've spent time contemplating the circumstances of my own death. Where will I be when I die? Who will be present? What will the doctors be doing—or will there even be any doctors in the room?

The more involved we are with the dying, the more these kinds of thoughts tend to push into our consciousness. I've seen people die in all sorts of places and under wildly different circumstances, so I can't help but wonder whether there isn't a better way to plan ahead.

Some of the most memorable experiences from my internal medicine training were mishaps that occurred around what I thought would be a well-orchestrated death. In one instance, a patient with advanced AIDS was admitted, comatose and hopelessly ill. We spent the night helping the family come to terms with his imminent death. They signed a do not resuscitate (DNR) order, only to have an attending physician talk them out of it the next morning because he wasn't convinced that they were the appropriate surrogates. Another patient, elderly and frail, was dying at home. During the course of several months, she made her wishes known: no heroic measures, no artificial life support, no hospitalization under any circumstances. Yet as soon as she slipped into a coma, her son—who hadn't been actively involved in any aspect of her care—called an ambulance and had her hospitalized. She died several agonizing weeks later in the hospital intensive care unit.

Orchestrating Death

THESE DAYS, I'M AN INTERNIST IN MANHATTAN and work in Mount Sinai's Visiting Doctors Program, which provides primary care for homebound people. Our patients are generally elderly and infirm, and a good number of them are in the late stages of long-standing illnesses. Many are terminally ill and express the desire to die at home.

Our program works closely with home nursing agencies, home hospice services, and a wide array of community-based agencies to create a network of support that allows our patients to remain with their families in familiar surround-

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David Muller (david.muller@mssm.edu) is an associate professor and dean for medical education at the Mount Sinai School of Medicine in New York, New York, where he works in Mount Sinai's Visiting Doctors Program. The name of the patient in the story has been changed.

ings to the very end.

To my mind, this is what patient-centered care is all about. In their own homes, our patients and their families feel comfortable taking matters of life and death into their own hands. If it suits their needs, and it usually does, we will do whatever is necessary to keep them away from the emergency room and out of the hospital.

For a doctor, a home visit lies outside the hectic pace of traditional hospital and clinic settings; it provides a chance to go beyond the thumbnail sketch and curbside consult that rarely do patients justice. Communication—and the high-

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quality care that results—takes time because questions have to be answered, details spelled out, reassurances given, and the whole lot repeated until everyone agrees and understands.

More than two-thirds of our patients are able to die at home. This is in sharp contrast to the national figure of two-thirds of patients dying in hospitals or skilled nursing facilities (often despite their wishes to die at home). We

think that our statistic is even more impressive considering how much effort and coordination it takes to get everyone on the same page. Everyone has to come to terms with death intellectually, emotionally, and spiritually. And everyone has to know what to do when the patient dies: Call the doctor, call hospice, or call the funeral home, but don’t call 911.

Mrs. Santos’s Story

WHEN I FIRST MET MRS. SANTOS IN HER HOME—in fact, every time I ever saw her—she was sweating and had a rapid heart rate. I soon came to understand that despite the smile this small, lively woman always wore, she was in excruciating pain. During an earlier hospital stay, our medical center’s palliative care staff was amazed at the doses of morphine-based pain killers needed to keep her symptoms at bay. Once Mrs. Santos’s pain seemed controlled and the care plan was clarified with her and her family, she was sent home to be cared for by hospice nurses and those of us in the Visiting Doctors Program.

Mrs. Santos was living just blocks from our hospital, in the projects of Spanish Harlem. Everything about these buildings is intimidating: their hulking size, the desolate look of the lobby, the smell in the elevator. Even the long, narrow hallways, although they aren’t longer or narrower than other hallways, can seem menacing to the uninitiated.

The two-bedroom apartment was clean but cluttered, with a seemingly endless stream of people, faces, voices. It was active, even animated—very much alive. On one occasion, late in Mrs. Santos’s care, I entered the living room and found ten

family members sitting around an enormous wire cage filled with crabs and chunks of coconut. They'd let the crabs feed on coconut for a few weeks, I was told, and then have a real Dominican crab feast. They were all sitting around watching the crabs grow.

On my first visit, Mrs. Santos was waiting for me in her bedroom. It was filled almost to capacity with her hospital bed, oxygen compressor, hydraulic lift for getting her out of bed, bedside commode, and medicine chest. I alternated between sitting on the radiator and standing. She was fifty-two years old and dying of widespread cancer. Her cancer almost filled her abdominal cavity; it had spread extensively throughout her lungs; and a large mass near her spine was crushing her spinal cord, leaving her paralyzed from the waist down. She had an enormous bedsore. She also had severe shortness of breath and required supplemental oxygen.

Immobilized in bed, Mrs. Santos was always impeccably clean and always smelled good. She also was the most stoic person I'd ever met. Whether it was her deeply held religious beliefs or her devotion to and passionate love for her family, something kept this remarkable woman suspended above her travails. She smiled through it all, even when she was smiling through clenched teeth.

After her most recent hospital stay for pain management, during which the children had battled openly among themselves about where their mother should go after leaving the hospital, one of her daughters had taken charge and taken her in. Mrs. Santos had raised five children as a single parent and loved them all equally, which made the thought of living with only one of them awkward for her. Her other children remedied this by visiting often and filling the apartment with her grandchildren at all hours of the day and night. For her part, she was happy to be in a family home, happy to be surrounded by family.

She was also in great pain. The usual starting dose of oral morphine is 5 mg every two to four hours. When I met Mrs. Santos, her intravenous pain regimen was the equivalent of about 500 mg of oral morphine every hour.

Although her family understood that she had very little time to live, Mrs. Santos insisted that she would be fine and refused to discuss matters further. She was willing to appoint the daughter in whose apartment she lived as her health care proxy, but, other than agreeing to a DNR order, she wouldn't specify her wishes for end-of-life care, refusing to discuss such things as whether she would accept artificial nutrition and hydration. We completed, and I signed, an out-of-hospital DNR form, and I made sure that the Visiting Doctors' phone number was prominently displayed. Mrs. Santos spoke no English, and I hadn't had the good sense to learn Spanish, so her daughter served as translator. Our direct communication was limited to sparkling smiles (hers) and knowing glances (also hers). She was fortunate to have a caring and devoted daughter who was determined to give her the same loving care that her mother had shown in raising her children.

Preparing for death has its own ritual. It requires many family meetings, innu-

merable phone calls, lots of reassurance, and a great deal of reinforcement. It is critical that the family and patient have easy and immediate access to a nurse and doctor, as well as proper documentation at home on the patient's wishes about resuscitation, including—and this is essential—an out-of-hospital DNR form.

New York is one of the more than twenty states that has an out-of-hospital DNR law intended to ensure that emergency medical services (EMS) personnel do not resuscitate terminally ill people at home against their wishes. If EMS personnel are called to the scene, they are required by law to perform life-saving measures unless there is an out-of-hospital DNR form or an EMS-affiliated doctor orders them not to resuscitate. Although many patients have thought through their advance directives and have living wills and health care proxies, none of these are valid in the home setting. Presumably this is because it's unreasonable to expect EMS personnel to read and interpret the validity of these documents during an emergency.

I visited Mrs. Santos at home once a week. At every visit she went to great lengths to convince me that she was feeling OK, her appetite was excellent, she was eager to be out of bed, her pain wasn't that bad. The truth was that before entering Mrs. Santos's room, I would get a reality check from her daughter. It was

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during these hallway discussions that I found out how much time her mother spent crying and trembling from pain every day, and how she begged her mother to accept a rescue dose of pain medication that was invariably refused. Despite Mrs. Santos's stoicism, we had to increase her pain medication, and by the second week she was intravenously getting an hourly equivalent of almost 1,200 mg of oral morphine.

Her five children were always present in some combination, and the apartment was teeming with grandchildren sneaking in to steal a curious peek at Grandma and getting a knowing wink for their efforts before an adult shooed them out.

As the weeks passed, Mrs. Santos and I developed our own rapport. I tried hard to respect her wish that the pain medication not be increased, despite her escalating pain, if it was going to make her sleep all the time. And, in response to a food craving she repeatedly mentioned, I surprised her one day with a double cheeseburger and fries from McDonald's. I was as good as family after that.

Other than her inexorable decline, the visits were always the same. Mrs. Santos never stopped talking to me about her family, and she never agreed to aggressive pain control that would make her lethargic. By the fifth week, and my fifth visit, she began to accept that she was dying. She was profoundly emaciated, sweating profusely, and burning with fever. Crying and barely able to speak clearly, she asked that we call her priest and agreed to have stronger pain medication once she had made her peace with God.

When I visited four days later, she had seen the priest, and her entire family had gathered to say goodbye. She had not spoken in forty-eight hours and was unresponsive. We increased her pain medicine one last time, and the family and I once again reviewed what needed to be done when she passed away.

The Plan Goes Wrong

THE FOLLOWING AFTERNOON I GOT A CALL from my office that Mrs. Santos's family needed to get hold of me right away. I called, and when someone on the other end picked up, all I heard was screaming, crying, chaos. Mrs. Santos' daughter yelled over the din. "They're doing things to her! You have to make them stop! They won't let me in the room!" I managed to blurt out a few words. "Who? What are you talking about?" The daughter told me. "EMS came and they're doing things to her. I think the neighbors called them, and they won't stop doing things to her!" Still confused, I asked, "What are they doing?" Her frantic reply: "She died half an hour ago! Then they came into my apartment, and they won't stop working on her! They say I don't have the paper and they won't leave her alone!"

It was then that I realized what had happened. Mrs. Santos had died a peaceful death, the death she and her family had hoped for. Her bereaved family, especially her young grandchildren, had begun sobbing so loudly that a neighbor heard and called 911. When EMS arrived, they demanded to see her out-of-hospital DNR form. Then, when the family couldn't produce it, the emergency medical technicians (EMTs) put her on the floor and proceeded to perform advanced cardiac life support on Mrs. Santos' dead body. They wouldn't stop, wouldn't speak to my nurse when the panicked daughter first called for help, wouldn't speak to me on the phone, and had locked the family out of the bedroom.

Fortunately, Mrs. Santos' family lived only a few blocks from our office. I grabbed a blank out-of-hospital DNR form as a precautionary backup, filled it out, and signed it. Then I hopped in a cab and rushed toward the apartment. The trip took less than ten minutes, but it was enough time to allow me to go from being blind with rage to rational decision-making mode. I'd started the ride hoping for a confrontation with EMS that would involve the police, but by the time I was in the building's elevator I was calmly considering my options depending on the response EMS had to me and the out-of-hospital DNR form I held in my hand.

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By the time I arrived, the entire family was gathered in the living room, and the EMTs had barricaded themselves behind the door to Mrs. Santos's bedroom. When they finally opened the door to let me in, the sight was horrifying. This

long-suffering woman, who had been so carefully cared for in her last days by her family, was on the floor, stripped of everything but a diaper, hooked to a cardiac monitor, an endotracheal tube jammed down her throat. She was even getting IV fluid pushed into her veins. There were six EMTs in the room, and clearly there was resentment, suspicion, even anger at my arrival. But there was also shame and some vacant “just doing my job” looks. Two of them wouldn’t (couldn’t?) meet my gaze. They checked my credentials and accepted the out-of-hospital DNR form I’d brought—at which point the daughter politely but firmly threw them out.

But Don’t Call 911

HISTORICALLY, THE OPTION TO REFUSE cardiopulmonary resuscitation (CPR) exists because of resuscitation’s dismal success rate: only 1–2 percent for out-of-hospital sudden cardiac death. And that’s for a typically healthy businessman who collapses on the subway platform from a heart attack, not for someone dying of a terminal illness.

EMS protocol is obviously designed to protect patients and families—as well as EMS personnel. No one wants to make a judgment call in the heat of the moment and with inadequate supporting information that withholds needed treatment. Yet this well-intentioned policy can fly in the face of everything that families, nurses, and doctors do to help people die quiet deaths at home. That’s what went wrong for Mrs. Santos.

A piece of paper that provides an out-of-hospital DNR order is easily misplaced, as Mrs. Santos’s family tragically discovered. That’s probably why wearing a low-tech DNR MedicAlert bracelet is slowly gaining acceptance. Typically, these bracelets convey clinical information to EMS personnel in situations where the patient can no longer communicate. The bracelets are accepted as an advance directive in many states—although not in New York, so it wouldn’t have helped Mrs. Santos. It is a seemingly foolproof method of communicating a patient’s end-of-life wishes.

Reaching an understanding on quality-of-death issues with dying patients such as Mrs. Santos is part of good doctoring. In health care, and especially in home care, the combination of clear communication and time work to create a harmony that is the backdrop to a well-orchestrated death. It’s also the only way to try to safeguard patients’ wishes in a disturbingly unpredictable world.