

When death is imminent, end-of-life care decisions sometimes go out the window

Two medics roll Mrs. M into the emergency department. Sweat drips from her forehead. Her chest heaves in and out as she tries to suck every last oxygen molecule from inside the oxygen mask. I introduce myself and she opens her eyes but her glassy stare lands beyond me. “She has metastatic breast cancer,” says one of the medics. “She’s in hospice. But her son wants everything done.”

“Doing everything isn’t a plan that’s compatible with hospice,” I mutter.

“We didn’t know what to do,” says the medic, shaking his head. “She wasn’t this bad when we arrived at her home. She was working to breathe, but not like this.”

Hospice care aims to provide compassionate care for people near the ends of their lives. This type of team-oriented medical care focuses on controlling pain and other symptoms and meeting the emotional and spiritual needs of patients and their family members. Although some hospice care is provided in special centers, most is provided in patients’ homes. Hospice workers may visit daily to help their patients die with dignity and free from pain.

That should have been what happened with Mrs. M (not her real name). But her son called 911 and now she is in the emergency department. I ask the medics for any hospice-related paperwork. They raise empty hands. There’s no advanced directive meaning no documentation telling me what kind of end-of-life care Mrs. M wanted — or didn’t want.

“Is her son here?” I ask.

Paul (not his real name) is a thin, nervous man; his windbreaker is zipped to his throat. In a trembling voice he describes how his mother hadn’t been feeling well all day and had gotten worse during the evening.

“Please, doctor, do something,” he says.

It’s neither a request nor a demand. It’s a plea that contains a quiet emotional force and presumes we share a common understanding on one key point: what that “something” is.

I must take some definitive action very soon. Normally, the lungs take in oxygen and expel carbon dioxide. Monitors show that not enough oxygen is reaching Mrs. M’s bloodstream and carbon dioxide is building up to a dangerous level. That’s partly why she’s so somnolent. A portable chest X-ray reveals lungs overrun with cancer and a cloud suggesting pneumonia.

Although most Americans say they want to die at home, many die in hospitals. That's due to a range of factors, including challenges in end-of-life planning and communication. An effective and meaningful process requires several elements to be in place. Patients must discuss their goals of care with family members and health care providers. These wishes and discussions must then be documented, kept up to date, and made available to emergency providers like me who, confronted with hard decisions under pressing time constraints, could desperately use some guidance.

When a patient no longer has the ability to make decisions, designated Substitute Decision Makers (SDMs) — which is what I assume Paul is — make decisions as the patient would have, meaning consistent with their wishes and goals. But I've observed how even the most loving, informed, and prepared SDMs can be knocked off balance when the moment finally comes to make decisions.

I explain to Paul that his mother will die if I don't insert a breathing tube into her airway and connect her to a ventilator. He nods. He knows those interventions won't cure the irreversible metastatic breast cancer that's killing her. He confirms her wish for hospice care. I ask what he understands hospice to mean.

But he answers a different question. "Do everything," he says.

I bite my lip, quickly turning away so Paul won't see the heat beaming from my eyeballs. And I'm suddenly ashamed. He seems so fragile. I worry that my frustration will shatter him into pieces. But I have a dying, barely responsive patient who is unable to speak for herself and a family member begging for treatment that, to the best of my knowledge, contradicts her wishes.

Mrs. M weighs more than 300 pounds. The oxygen mask conceals a small mouth. She has a short neck and many chins. These physical attributes are important because it will likely be a challenge to pass a breathing tube down her throat. Medications to relax her airways aren't working. And she's too sleepy for a BIPAP mask, a form of non-invasive ventilation for acute respiratory failure that might otherwise buy us some time.

The nurse I am working with shoots me a look, *that* look, a wordless kick in the ass. We don't have time.

As I describe what it will take to "do everything," Paul scrunches up his face. We will first try to intubate Mrs. M, which means putting a breathing tube down her throat and into her airway, then connect it to a machine that will breathe for her. If we can't intubate her, we will cut into her neck with a scalpel and insert the breathing tube below her vocal cords, a procedure known as cricothyroidotomy. To me that is cruel and unnecessary treatment for someone who likely wants comfort measures only. It also puts the physicians and nurses caring for Mrs. M into a morally distressing position.

I then detail the comfort care we would provide his mother if we honour her wishes. It includes giving her oxygen, controlling her pain, and using medications to mitigate her shortness of breath and air hunger. The goals of that care — to relieve suffering — are different, but would be just as aggressive as “doing everything.”

I tell Paul, “We’re staying right here. We won’t leave your mother alone.” I’ve cared for patients or families who choose to “do everything” even if it’s not what they desire out of fear their loved one will otherwise be abandoned.

He suggests that we wait. He needs to talk to his sister. It’s almost 2 a.m. and she’s at work. I shake my head. Indecision is the worst possible decision.

“She’s coming. She should be here in an hour.”

As an emergency physician, my goal is to save lives. But I can also help provide patients with good deaths. From my perspective, you usually have just one chance to do that, and this one is slipping away.

Advanced directives speak for us when we lose the mental capacity to speak for ourselves. They chronicle our values and beliefs, what brings us joy, the burdens we’re willing to endure for an acceptable quality of life, and when we’d refuse or stop treatment.

I wasn’t sure what Paul understood. Sometimes, family members are overwhelmed by making potentially life-changing decisions for their critically ill loved ones. The experience can produce profound emotional consequences later on. Though I was horrified by the possibility of performing lifesaving measures on a patient who apparently had other preferences, I wasn’t in a position to unilaterally decide that “doing everything” was inappropriate.

Unable to contact Paul’s sister, and with Mrs. M deteriorating quickly, I decide to intubate her.

I am grateful that the breathing tube slips in easily. For the moment, Mrs. M is stable and sedated, a ventilator breathing for her.

But now *I’m* distressed. Intubating her feels wrong, though necessary given the circumstances.

I finally have a chance to dive into Mrs. M’s medical records. The electronic medical record should make locating and honouring advance care planning information easier, especially in emergency settings where having this information readily available helps provide care that aligns with the patient’s wishes. But this documentation, even among older patients, often isn’t available.

I find a note in the record from Mrs. M’s oncologist. Earlier in the week this doctor told Mrs. M that she had a month to live, maybe two. Mrs. M then refused any further chemotherapy and said she didn’t want to be intubated or receive CPR. It was at this visit that her oncologist

referred her to hospice care. The note also alluded to difficult conversations with the family, who were less accepting of Mrs. M's prognosis than she was.

Paul's sister, Violet (not her real name), finally arrives. Like me, she's dressed in scrubs, having been summoned from her work at a nursing home. Even after I share with her and Paul what I read in her mother's medical record, Violet insists that we keep her mother on the ventilator.

"Please?" she asks.

The ventilator breathing for Mrs. M has been giving her tissues oxygen while blowing off carbon dioxide. She gradually becomes more alert. Soon she's gesturing to pull out the breathing tube.

"She wants to talk," Violet says.

"To do that, I'll have to take out the tube," I say.

"We know she's dying," Violet says, her teary eyes turning to her mom. "We were hoping for a little more time."

I have heard this many times from families. Their expectations might seem unrealistic, but they're doing their best to keep the reality of death in the future. There is a profound difference between the idea of dying when death is an omnipresent shadow on some distant horizon and when it is happening right now.

We give Mrs. M morphine to keep her comfortable and pull out the breathing tube. She shares kisses with Violet and Paul. We pull in chairs and her family gathers around the emergency stretcher.

"She raised us all by herself," says Violet, holding her mother's hand. "She worked every day, I mean every day, to support us. She is a fighter, the toughest woman you ever met."

I look at Paul, sitting beside his mother and rubbing her arm. Of course he was going to insist on doing everything — what the oncologist and providers like me consider compassionate care is, in his mind, giving up.

Mrs. M's breaths are slow and shallow. Sister and brother collapse into each other's arms. I take over holding Mrs. M's hand, almost as an apology for what I'd done. I could have framed the discussion with her children differently, recognizing not only their mother's wishes but supporting the emotional needs of the decision-makers.

In a 1995 article, bioethicist Daniel Callahan wrote, "Is death a friend or an enemy, to be acquiesced to or to be fought?" He said that the American health care system isn't sure how to answer that question. I think the same holds true for most families.

A peaceful quiet takes over the room. For the first time I notice gratitude in Paul's and Violet's faces. A nurse lowers the lights in the room and shuts off the monitor. Mrs. M's breaths come more slowly, her chest barely rising with each one. I breathe a silent sigh of relief, grateful that Mrs. M got a second chance at a good death.

Adapted from: <https://www.statnews.com/2017/12/14/end-of-life-care-decisions/>

