

# Beyond Code Status

Louise Aronson, M.D.

Usually when the phone rings in the middle of the night, my spouse and I leap up thinking, “Which one?” meaning which one of our three remaining parents — who are 88, 89, and 90 years old — is in crisis. Or dead. At 1:30 in the morning on a Wednesday last September, we knew the call would be about my mother.

The voice at the other end of the line announced that he was a doctor and said he needed my permission for a blood transfusion.

Why, I asked, did my mother need a transfusion? And why, I thought, was she unable to consent herself?

This might be a good moment to insert some backstory.

A week before the phone call and a month shy of her 90th birthday, my vaccinated and boosted mother nevertheless got sick with Covid-19 for the first time. Days later, she seemed to have fully recovered when, on what began as a normal Sunday morning with the *New York Times*, she found herself on her kitchen floor bleeding from her head. She had moved to assisted living years earlier for the sake of my father, who had since died, and when she realized she couldn't stop the anticoagulant-fueled bleeding, she called for help. Seeing what looked like a B-movie murder scene, the facility staff dialed 911. A few hours later, when I joined her in the emergency department of our local trauma center, my mother

was her usual self, except for the blood matting her hair and staining her neck and arms. A CT scan confirmed only external injury, so the plan was sutures and admission for syncope. I wondered whether to prepare her for the inevitable shaving of her already thinning hair.

having cartoon-scale rigors. Her blood pressure, which had been in the high double digits on my arrival, dropped with each cycle of the blood-pressure cuff. As her systolic reached 50 and her pulse remained in the 40s, the trauma room filled with doctors and nurses. I texted my sister so

*In her clearest, loudest voice of the afternoon, she announced that she'd had a good, long life, wasn't brave, and definitely did not want intubation, resuscitation, or anything else that might cause her discomfort.*

In the first draft of this essay, I wrote that I couldn't remember what we talked about in that trauma room, a fact that might speak to the stress of the weeks that followed. Or maybe it's guilt. Because for more than an hour before she crashed, my mother's only concern was feeling cold — and neither I nor the other health professionals coming in and out of the room registered the symptom's significance. The intern said it would be warmer upstairs. A nurse brought a warm blanket that was only briefly helpful. I tucked it in around my mother and rubbed her arms.

As the admission team finished their assessment, my mother began

my first message wouldn't be that our mother was dead. The team asked about code status.

Luckily, my mother had been talking about her death since my internship in 1992. As she'd moved through her 80s, the frequency of these conversations increased, but she never wavered in her preferences. She now told the team that I knew what she wanted. I explained, then turned to her for confirmation. In her clearest, loudest voice of the afternoon, she announced that she'd had a good, long life, wasn't brave, and definitely did not want intubation, resuscitation, or anything else that might cause her discomfort. Her animated certainty made the

note-taking nurse laugh and the doctors smile.

Although frail, my mother had been happily independent. She'd lost a lot of blood, so we decided on fluids and a brief trial of a single pressor, with admission to the coronary care unit (CCU) for stabilization. The resident said it was hard to do pressors without a central line. When I explained to my mother what a central line was, she asked if she had to do that. Small, pale, and shivering, she repeated that she didn't mind dying, she just didn't want to suffer, and a central line sounded like suffering to her. I suggested that the line wouldn't change the care plan anyway, since if the pressor didn't help we would choose palliation, not escalation. The team agreed.

Thus began her first hospitalization in 30 years. She came off the pressor within hours, but her troponin peaked in the 6000s, and an echo showed new abnormalities. The cardiologists wanted a catheterization, an approach that seemed both potentially helpful and totally counter to her goals of care. I asked colleagues for advice. Do it, they all said, and my mother agreed. The day before the transfusion phone call, a senior cardiologist marveled that my mother's largest coronary lesion was under 20%. She had a cardiomyopathy from Covid-19 or hypotension or both, and a good recovery could be expected. When we left that night at the end of visiting hours, her mind was clear and her spirits good.

What happened next went something like this: my mother choked on a pill, went into rapid atrial fibrillation, and her blood pressure plummeted. The on-call

team, suspecting catheterization-related injury and bleeding, started multiple pressors, scheduled a pan-scan, and put interventional radiology on alert. If transfusion hadn't required my authorization, they wouldn't have called.

While the resident rattled off his plan, we turned on our bedroom light and started getting dressed. My mother was dying, and I wanted to be there.

I tried to explain to the resident that none of that should be happening, that we hadn't agreed to more pressors, that a scan wasn't needed since a procedure was out of the question. The resident didn't want to discuss goals of care and advance directives. He was in a hurry. I said I was coming in. He said I couldn't, the charge nurse wouldn't allow it. Visiting hours were over.

On the one hand, I can see how finding my mother in the CCU after cardiac catheterization might have led to aggressive care. On the other, we had had a very detailed conversation about my mother's wishes and priorities in the trauma room. Evidently, that information didn't make it into her record, even though she was a very old<sup>1</sup> woman with frailty,<sup>2</sup> Parkinson's disease,<sup>3</sup> cognitive impairment, and a gait disorder necessitating a walker,<sup>4</sup> all of which increased her risk of hospital complications, significant decline in functional status (an outcome that to many people, my mother included, seems worse than death), and death.

It's worth noting that although I am a White, native-English-speaking senior physician at the same umbrella institution, even I couldn't control what hap-

pened next. Hospital security understood "dying mother" and let us in, but both doctors and nurses repeatedly refused us entry to the CCU. Three hours later, when they finally opened the doors, it was too late. I took a photo of the lines and bags of medications at my mother's bedside. She was distressed and confused. They had done everything she had so eloquently asked them not to do, and I had been powerless to stop them. All that had been documented of our trauma room discussion was "DNR/DNI."

After more than 2 months of the sort of misery she had always hoped to avoid, my mother is now back in her apartment and doing well. Hearing that, the doctors who "saved her life" might think they were right to do so. The kind and dedicated cardiology team clearly believed they were making the best decisions that night, so we may just have to agree to disagree. As a daughter and geriatrician, I have a different perspective: that it wasn't their preferences that mattered; it was my mother's.

Periodically, I ask my now 90-year-old mother if she'd still rather be dead. Yes, she always says without hesitation, then adds that she's not depressed but she's had a good life and really wanted the quick, painless ending she didn't get.

Everyone dies. In medicine, we need to expand our definition of "saving" to include doing our best to "rescue from harm or danger" at the end of life as well. For patients who are very old or very sick,<sup>5</sup> code status is just one small part of the most important conversation of their admission.

Some identifying details have been changed.

Disclosure forms provided by the author are available at NEJM.org.

From the Division of Geriatrics, Department of Medicine, University of California, San Francisco, San Francisco.

This article was published on April 20, 2024, at NEJM.org.

1. Chodos AH, Kushel MB, Greysen SR, et al. Hospitalization-associated disability

in adults admitted to a safety-net hospital. *J Gen Intern Med* 2015;30:1765-72.

2. Evans SJ, Sayers M, Mitnitski A, Rockwood K. The risk of adverse outcomes in hospitalized older patients in relation to a frailty index based on a comprehensive geriatric assessment. *Age Ageing* 2014;43:127-32.

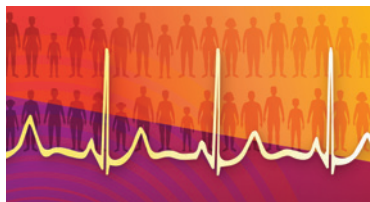
3. Vignatelli L, Zenesini C, Belotti LMB, et al. Risk of hospitalization and death for COVID-19 in people with Parkinson's disease or Parkinsonism. *Mov Disord* 2021;36:1-10.

4. Studenski S, Perera S, Patel K, et al. Gait speed and survival in older adults. *JAMA* 2011;305:50-8.

5. Rubin EB, Buehler AE, Halpern SD. States worse than death among hospitalized patients with serious illnesses. *JAMA Intern Med* 2016;176:1557-9.

DOI: 10.1056/NEJMp2314068

Copyright © 2024 Massachusetts Medical Society.



“Intention to Treat,” a podcast drawing on the deep expertise of the *New England Journal of Medicine*, offers breaking news, enlightening context, and incisive analysis of critical and urgent issues in medicine and health care.



**Listen to the latest episode at NEJM.org or wherever you get your podcasts.**