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THE END

The I.C.U. Is Not a Pause Button

By **Kristen McConnell** August 26, 2015 4:15 am

The End is a series about end-of-life issues.

With my elderly stroke patient's back arched and his head tilted back, too many angles of his skeleton were on display. A nose covered in thin gray skin sliced the air like a shark fin, and beneath it his mouth hung open. He didn't look like he was resting.

Another nurse walking by put it bluntly, as nurses tend to do. "Is he alive?"

Of course he was alive. We could both see the safe numbers and steady waves marching across the monitor. Only the measure of the oxygen circulating in his blood hovered low. He had stabilized and had been taken off his ventilator, but his body wasn't rising to the challenge of consciousness and physical independence. For a few days we had used CPAP (continuous positive airway pressure), a device that pushes oxygen through a mask and is one step away from intubation. But CPAP is meant for people who are awake and able to pull off the mask if, for example, they throw up and the machine begins to push vomit into their lungs. He was no longer a good candidate for it, and now we were trying not to use it. Of the many devices available to support breathing, none of them was a good solution for him.

His family knew that he wasn't breathing enough, and wasn't awake. It

wasn't pneumonia or lung disease and it wasn't a result of neurological damage from his stroke; he was just weak and not well. He was facing being intubated again, and it was clear that if he went back on a ventilator, he would need it for the rest of his life. His wife and children were talking about making his status "do not resuscitate/do not intubate," but they hadn't decided, and they were waiting for a son who lived far away to weigh in. And it was the weekend. Staffing was low in the I.C.U.; no attending physician was present; and things were on pause.

Except of course they weren't. The patient was living through these hours and days, mask on, mask off, a feeding tube in his nose, IVs in his arms, having his dry mouth sponged, his throat suctioned, defecating and being cleaned up. He was alive, and while he wasn't in pain, he wasn't passing the time pleasantly.

I was on a 12-hour overnight shift. My next patient arrived around midnight. As I watched him being wheeled in from the emergency room, I thought he had a skin condition, but when we hauled him onto the bed I realized that his face and neck were covered in dried vomit. The E.R. staff had been too busy trying to stabilize him to wipe him off. He was in his 30s. He had chronic pain and had taken narcotics, and his girlfriend found him unconscious.

He was seizing continuously, and after doing a combination of not breathing and inhaling vomit for some time, his lungs were in very bad shape. His blood pressure needed to be artificially maintained, and because his glucose remained high even after plenty of insulin, we started an insulin drip too. He was sick.

After spending the first half of the night caring for the old man next door, I was drawn away from him, but I watched closely enough to know that despite my sitting him up in bed and giving him as much oxygen as I could, his breathing was getting worse. The doctor knew that the family was considering

switching to comfort measures only, and hoped not to escalate his care. But while the doctor stood over the young, critically ill man, placing an arterial line in his groin, working steadily to save him, I had to point out that if we didn't put the old man back on CPAP soon, we'd end up performing an emergency intubation.

From behind his sterile mask came the doctor's exasperated sigh. "What we're not doing is helping him."

As if I didn't know.

But our job was to provide intensive care. We didn't have the choice to let him slowly stop breathing. We had to tailor our care to the numbers on the monitor and the orders in his chart. That night, we put the him back on CPAP. When I came back to work 12 hours later, he had been intubated — a hard plastic tube pushed through his mouth down his trachea, taped to the delicate skin of his face. The younger patient, meanwhile, had started breathing and moving his limbs.

On my next shift two days later, the old man's room was empty. His family had gathered, seen him back on the ventilator, and asked to stop treatment. Not atypically, he had died after a couple of weeks of maintenance by intensive medical care. And the other patient? I smiled when I saw on the nurse assignment sheet that he had "boundary issues," and a few minutes in his room confirmed this. Inappropriate and annoying: a status reserved for only the healthiest of I.C.U. patients. We had simply and decisively saved his life. This is what I thought I'd signed up for when I took the job, but I had rarely experienced it in my two years as a nurse.

When I first realized that in intensive care we held lives in limbo more often than we saved lives, I asked a friend who was a more experienced nurse how she felt about that. She said that sometimes a stay in the I.C.U. lets a patient's family prepare for his death. But while it may soften the shock of death for the family, being in the I.C.U. is unpleasant and bizarre for the

patient.

I've often spoken with patients' family members who seem to feel that an I.C.U. is a time-free holding zone; that intensive care functions as a pause button. Those conversations usually take place on the phone. It's harder to believe in this pause button when you witness the constant poking and suctioning, the invasive examining and monitoring, the parade of medications and the contraptions necessary to deliver them, the lights and alarms, the coughing and grimacing and shuddering — or, in the less responsive, the bloating and stiffening or slackening and eventually the eerie dehumanization of both the patient and the caregiver. Thinking that intensive care can pause the march of time is a misunderstanding or a willful fantasy. There are always bargains to be made and discomforts to be faced in a place that is staving off death.

Time goes by quickly caring for patients like that young, scarily ill man. It goes by too quickly for nurses and doctors to eat or sit down or even go to the bathroom. It went by too quickly for the E.R. staff to clean the vomit off his face. Each minute matters, and it feels like a focused race. Caring for patients like the old man doesn't feel like racing, it feels like waiting. In cases like his, time goes by slowly. But it definitely does not stop. These days are lived. For patients in the hospital surrounded by workers just as for patients at home or in hospice surrounded by people they love, these days at the end count.

Americans are increasingly aware that a good death rarely happens on its own; it needs to be negotiated and orchestrated. More people complete advance directives so their families are not left to make end-of-life decisions for them. But every day thousands of the patients toughing it out in intensive care are in fact in a purgatory maintained by family members who are either too intimidated by the complex medical situation to get involved (care providers who communicate poorly share the blame for this), or who don't realize that this time is crucial. The cascade of responsibilities that occur when someone is dying has begun, even when the nurse on the telephone tells you

that the patient is stable.

Families should realize that this time is the end of life, and they should pay attention to its quality just as they would if the patient were dying at home. That's because although we can usually hold off death, we cannot pause time, and an extended stay in the I.C.U. is an ugly way to end a life. Unless the medical record contains an order limiting the measures that can be taken, originating from the patient, his next of kin or his designated proxy, interventions to keep him alive will continue indefinitely, regardless of the anticipated outcome in quality of life.

When a family member is in the I.C.U., it's not enough to call. You need to drop what you're doing and be at that person's side, figuring out what is best for them. Doctors, nurses and technicians care about patients, but sometimes we cannot express our care by doing what we think is best for them. In the I.C.U., that is not our job. Our job is to preserve life. Often, when working with patients who have a quality of life it is impossible to imagine anyone wanting, we express our care by saying, "I'm sorry."

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