

First, Do No Harm

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As I first form these words (whispering them into the note section of my phone while lying on a makeshift bed in the corner of a hospital room) I find myself on the patient's side of an end-of-life conversation and it is not going well.

My 88-year-old grandmother survived breast cancer 15 years ago and was diagnosed with renal cell carcinoma last year. Given the size of the tumor and her medical comorbidities, we were unable to intervene. Now she's hospitalized with hematuria, urinary obstruction, and cystitis.

I initially follow her hospitalization through daily FaceTime phone calls. I ask her about the hospital food. She likes it. I learn the name of the phlebotomist she likes because they always get her "on the first try." I show her my cats to cheer her up. It's December and she loves Christmas, so she shows me the small tree and garland that the family has brought in to decorate her room.

After a week in the hospital, however, we notice a change. She's confused, somnolent, not eating. At first, I reassure my family that this could be sundowning, but she quickly deteriorates. On hospital day 10 my aunt calls me at 4 AM because a rapid response has been called—they're asking to intubate her. I'm too far away to ask for medical information but we know her wishes and we remind everyone on the team she is DNR/DNI. She is placed on a non-rebreather and transferred to the telemetry unit. I don't go back to sleep that morning; none of us do. I grab a blanket and go out into the brisk December sunrise. Later that day I fly across the country.

When I land, I go straight to her. Was there a glimmer of recognition when she made brief eye contact with me or is that wishful thinking on my part? That first night is not restful; she's unsettled, grunting, moving, tugging at her mask, shaking her head. The team comes in to start a new bag of antibiotics, adjust the tele that has disconnected, fix the pump that's beeping, and repeat. They are gentle with her. The next day, I lead the family meeting with her team.

Without identifying myself as a physician so the team uses language the entire family can understand, I ask direct questions, but get vague answers.

When I ask for an update, I am met with numbers: hypercalcemia, hypertension, tachycardia, hypoxia. When I ask what is causing her clinical decline, I am told "her overall condition." When I ask what our goals of care for the day are, the answer is "hoping she responds."

Responds to what? I think to myself. She has cancer. She is desaturating on 15L with a non-rebreather, she's hypercalcemic from tumor lysis syndrome, and she's been delirious for the last 3 days. Unfortunately, none of this is mentioned by her team.

Through tears and with a lump in my throat, I ask about comfort care. Her hospitalist tells me that comfort care consists of administering morphine. I ask about consulting the inpatient hospice team, but there is no such thing. I ask about consulting the inpatient palliative care team, but there is no such thing. I ask about antipsychotics or anxiolytics, but all they can offer is morphine. I ask about withdrawing treatments and monitors and, without explanation, I am asked which treatments I would like to withdraw. There is a palpable tension within the silence of the room. No team member asks me any questions, and I don't have the energy to say any more. At the end of the conversation, I jokingly tell my family, "That doctor thinks I'm trying to kill my grandmother."

That night, her nurse comes in with PRN morphine orders. "The doctor ordered this to be given as needed for her anxiety. Do you want to give it?" I'm the palliative care team. I

manage her morphine overnight, evaluating her for agitation and signs of discomfort. She has a relatively quiet night.

The next day, I translate her clinical picture for the family. I don't have her lab work, images, pathology, or progress notes, but I know she's dying and there is nothing that can cure her. Our choice now is *how* she dies. I'm the hospice team. We gather and discuss when to withdraw her respiratory support and allow her to pass. I am left answering difficult questions: "Can she hear us?" "Is she suffering?" "Did we do something wrong?" "Won't she suffer without oxygen?" "Doesn't she need to eat?"

She gracefully bows out and exhales her final breath with her closest relatives at the bedside. She chose her time.

Having end-of-life conversations with patients and their families is one of my favorite exercises. It is challenging and meaningful. It is a great responsibility and, as most things in medicine, a great honor. However, when it was my turn to be on the other side of that conversation, I did not feel comforted.

I was *angry* that the burden of how my grandmother spent her last days fell entirely on us.

I was *disappointed* that the medical team caring for my grandmother was unable to translate the clinical picture to help guide the difficult decisions.

I was *disheartened* by how many patients are not given information or options. How much harm has been done because physicians didn't have the training, the support, the confidence, or the time? How can we better educate our residents or incentivize our systems to prioritize this care?

I was *relieved* for my family because we knew my grandmother's wishes, giving us the strength and the peace to honor her wishes.

My grandmother was lucky. Her granddaughter had training. I feel *confident* that I reduced her suffering and held true to my oath to first, do no harm.