

# CLINICAL NARRATIVE

It's early on in my shift, and the patient I've just met is already showing many signs of dying. I have been an RN on 3 North now for just over a year, and I've been caring for step down patients for a few months now. His name is Ned\*, a 91 year old man with a known history of lung cancer, and now his body is riddled with metastases –bone, brain, and liver. His battle seems nearly over; he is in and out of confusion and restlessness, seeing visions of his long deceased loved ones, he is nonresponsive with occasional exception to his daughter's voice, his breathing pattern is irregular, his lungs are overloaded with fluid, and his chest rattles with the secretions he cannot clear. Each nurse who came before me has already had extensive discussion with his daughter, Arya, about the direction he is headed and what to expect. Each nurse before me has come away bewildered and emotionally disturbed by one thing: Arya insists her father is a Full Code.

I, like many of my fellow nurses, believe that if a loved one were ever as close to dying as Ned was with as little hope of recovery, I would be morally obligated not to prolong their suffering. I thought I must be walking in to meet a grief-stricken daughter in such deep denial of her father's condition and so not ready to let go that she was selfishly allowing him to suffer. Arya was not at all what I expected. We sat down to talk, and before I could begin explaining her father's condition from square one again, she stopped me. "I know he's dying," she said, "and I know he won't recover. But he told me he wants everything done, and I have to honor his wishes. So please don't ask me to make him a DNAR again." At this point, she had tears in her eyes. I was floored by how hard she'd been fighting to honor a choice that wasn't hers for the love of a father she would soon lose. I cried alongside her, took her hand and told her no way was I going to ever ask her to dishonor her father's decision. The ensuing conversation revealed a deeper story: Ned was a devout Catholic with five children, two of whom had fallen away and rejected the Lord. Ned believed sincerely that his service and suffering in this life could redeem

his soul as well as the souls of his lost sons. Neither Arya nor I could understand or agree with that particular belief, but it was a part of him and he was clinging to it with his literal dying breath.

I would be lying if I said that knowing I was honoring Ned's choices erased the emotional warfare raging in me for the rest of the shift (and many days thereafter). I felt it grate on me every time we geared up for another repositioning, suction, or ABG. Anticipating the pain I would cause and knowing it wasn't going to stop him dying was some of the most intense spiritual distress I have experienced as a nurse. I did everything to lessen the discomfort—warm blankets, morphine, repositioning, pillows, cool cloths, clean linens, ice chips, decongestants, everything I could think of—but we still had to provide every possible treatment, no matter the discomfort it caused. With every intervention, Ned grew more and more restless. So I sat down on the edge of his bed, held his hand and stroked his hair, and I prayed for him. I prayed for his sons by name and for salvation for his family, for his life and his suffering to equal riches beyond measure in heaven, and for many other things. I sat at his side and whispered to him how much the Lord loved him and how much his daughter respected him. I promised him I would honor his choice and I would fight tirelessly for his life until his last breath. I told him I knew he had lived a life of faithfulness, that it was okay to let go, and that the Lord would meet him and tell him, "Well done, my good and faithful servant." I'm not sure if he heard any of it at all, but when I opened my eyes Arya was on the other side of his bed, holding his other hand and saying Amen.

She came to trust that I would advocate for her father, and when the hospitalist came around that day, I did just that. I couldn't let him go in without warning of the situation and let Arya, tired as she was, fight to persuade yet another healthcare provider to drop the word DNAR for good. I hovered by the room all morning waiting for him, and when he came around I gave the spiel Arya had been repeating ad nauseum—and being the compassionate physician he is, he listened. We spoke to Arya as a team and were able to reassure her that the

healthcare team would honor her father's Full Code decision. To my great pride, the physician also spoke to Ned as I had, offering reassurances that he was saved by the grace of God and his decisions were respected here at St. Jude Medical Center.

Fast forward one week and I'm back on the floor. I am assigned to Ned again, and I cannot believe he hasn't passed yet. I walk into the room. Arya cries tears of joy at my return and pulls me into a hug. Ned looks terrible. His eyes are glassy; his limbs feel refrigerated; his blood pressure is dropping. By 11:00 that morning, the time has come. His breathing is agonal. I call a Code Blue – and I advocate like I've never advocated before. Every doctor, respiratory therapist, pharmacist, and RN who gets a look at his history is (understandably) questioning his code status. Arya is outside in the hallway crying with the ARN, but she will tell me later that God placed me here for this: to be Ned's voice when he had none, to be his defender when his family was broken down, and to be his supporter when there was no time to explain what he believed. We work relentlessly on him for 40 minutes before we call the time of death. I know most of my colleagues feel the tension: How could we have put a sickly old man through the agony of a code for nothing? It feels like we have tortured him, robbed him of a peaceful death. But I have a little window into the man behind the sickness. He was full of unwavering faith and self-sacrificing love for the lost, and this was exactly what he wanted. Though none of us can imagine wanting to die like he did, we do know this: we helped Ned to die the way he wanted to, and so we have done our job well.

Ned was not the first patient I guided through the dying process, nor was he the most recent. He was never able to speak a single word to me, and I will never be certain if he understood any of the words I spoke to him. What I am certain of is this: Ned and Arya have redefined for me the task of advocating for these people I call my patients. It seems such a small thing now, but by respecting one choice I did not understand, I helped honor the dignity of someone's entire life and death.

\*Actual names have been changed to protect patient privacy