

***The Right Thing***  
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Sometimes, no matter how well-prepared you think you are, life has a way of sneaking up and pulling the rug out from under you. I had transferred to the Intensive Care Unit two or three months prior, completed the basics of training and orientation, and had been assigned to a regular shift. Many of our patients would stay with us for an extended amount of time, as it was a combined unit that took all comers. To add to the entertainment, this hospital was a teaching hospital, with a never-ending rotation of interns and residents learning their craft to complement the seasoned veteran nurses and neophytes like myself.

Mrs. J had been with us for a bit over a week, with a slew of medical compromises. I had taken care of her a few times, and her daughter, “June”, would occasionally be at the bedside. I happily went about my night, tidying, providing personal care, and checking items off of my list. June would sit and watch whatever daytime show happened to be on while her mother dozed. Mrs. J was always dozing, as she was quite ill and fading rapidly, despite every intervention. I always enjoyed being a part of rounds, offering a quick narrative of Mrs. J’s status and how she had weathered the night. After, I would listen in as the intern and resident would speak with June about the current goals for Mrs. J’s care.

When I returned from my two days off, I received report from the off-going nurse, noting that Mrs. J had deteriorated significantly while I was away. She no longer responded verbally and was rarely even alert enough to open her eyes. June had not been in over the last day, and had not seen her mother swiftly draw into herself. I practiced my ‘clinical detachment’, focusing on ticking off my checklist, tidying, bathing, and caring for Mrs. J. At the same time, a large part of me began to warily keep an eye on her, checking in more frequently. June came in and sat in her accustomed chair, speaking to her mother about small things, keeping up a running dialogue

that barely rose above the level of the television volume. I tried to remain in the background, giving them space, as I told myself. The determined cheerfulness of June's commentary made me inwardly wince, as nothing about Mrs. J's demeanor, color, or behavior gave any indication of improvement. In those rare moments when "nothing was going on", I would sit and speak with the interns and residents rotating through the unit, getting to know them as individuals and learn their patterns and personalities. It was easy to see which were truly interested in critical patients. We learned from each other, trading tips and tricks on how to keep the routine flowing smoothly. As Mrs. J started to turn for the worse, her intern continued to update her orders with this medication or that treatment. She steadily lost size, but not weight, as her abdomen swelled with fluid related to her condition built up. June was there more and more often, worriedly looking at all the equipment. I, was often paired with Mrs. J, for which I was grateful, and sad. I watched Mrs. J grow weaker and more fragile every shift, coming in one day to find that drains had been placed to relieve some of the fluid pressure. June rarely asked questions. I told myself that she understood what was happening, and that she did not ask because she knew the 'why' behind our interventions. I made a point of speaking both to Mrs. J and to June whenever I was in the room, not just because that is what I was taught, or because I was raised to be polite, but because a steady stream of conversation filled the quiet. No one teaches you how to accept the silence, whether you are the patient or the caregiver.

The turning point in my care for Mrs. J came on the day before she died. Despite our best efforts, Mrs. J had become unresponsive over the course of the last twenty-four hours. June continued to sit at her bedside, alternately holding her hand and talking. I noticed that the visits from the intern and resident became briefer, more focused on measurable data, without the longer dialogue about the trivialities of the day. The resident and I were at the desk, rapidly

clicking boxes and typing notes on our respective patients, chatting back and forth, when I asked when June was going to get “the talk”. There was a long look and a clammy silence.

I was stunned, to say the least. Of all the reactions I might have predicted, cold fear was not on my list. Surely, this was not the first time the topic of end-of-life had come up, was it? Apparently, it was not the first time; according to the resident, several conversations had been initiated among the physicians. No one had made the leap to having a discussion with June about her mother’s options. As a relatively new nurse, still fresh to the unit, I was hesitant to push too far, sure I would be speaking out of turn if I questioned too loudly this new information. At the same time, I was acutely aware of every desperate look I saw June give her mother, every fretful check of the monitors, every tightly grasped handhold. I questioned myself, and my training. The chart was complete, all boxes checked, and yet...were we doing the “right thing”? I spent the rest of that shift watching with new eyes. Each interaction between June and her mother, each intervention which I knew only delayed the inevitable, held new meaning for me. I was no stranger to loss in my own life, but this was my first experience on this side of the curtain. What was “best” for the patient, for the family? Who gets to decide? So many questions and all of them overshadowed by the feeling that we, as the professionals, should have the answers. June became increasingly tense, speaking more to me over the hours as I kept her now unconscious mother as comfortable as my resources could make her. Shortly before I left for the evening, June headed home for a much-needed rest, though we both knew that the term rest was a polite fiction. Before I left, I mentioned to the resident, again, that it might be time to have an important conversation with June. I received a noncommittal nod and the resident returned to writing notes.

I spent the drive home digesting my day. When I left that evening, her color was an indescribable blend of jaundice orange and waxy grey. Mrs. J was dwarfed by the blankets and

pillows used to prop her up, tuck her in, and keep all the tubes, lines, and wires conspicuously out of sight. On the outside looking in, we were battling death and making it look like a regimented and tidy battle. Why then, did I feel like there was an essential ‘something’ missing? When I returned the next morning, Mrs. J was more unstable than ever. I was shocked at how much change could take place overnight. As I began my morning routine, June told me how grateful she was that we were doing all we could to keep her mother alive. I didn’t know what to say. Once Mrs. J was tucked in, I excused myself and went to look for the resident.

I realized, after my conversation with June, that I could not politely wait for the logical conclusion to Mrs. J’s story without saying something. I had no idea whether I would be able to effectively explain myself or not, but I could not conceive the alternative: June standing by while we took those extreme measures made so famous on every medical drama. I found the resident, and explained my point of view. The resident made a vague promise to speak to the attending and see “what we could do”. A few more hours elapsed, and I became a hawk, peering out of the glass doors to Mrs. J’s room waiting for the attending physician to make rounds before lunch. June didn’t leave her mother’s side, and neither did I, if I could help it. Mrs. J lay there, shallowly breathing and so still that the monitors provided the only proof that she was still here.

Lunch came and went, without the attending. I began to get inwardly fidgety, wanting to push forward with a care conference before I lost my chance. I found the attending and, much to my good fortune, the resident. I repeated my earlier conversation, pushing for the physicians to speak to June before she left for the day. Through great perseverance, and not a little pressure on my part, I got all the parties into the closest conference room within half an hour. This was my first experience in an end of life conference. I wasn’t sure what to expect but I sat there and gave my presence to June. Once all of the technical specifics of the forms were explained, June was

given time to decide how she wanted to proceed. She sat there, clearly in distress after having been presented with so many options. I sat with her, silently, until she asked me what I thought. In the end, I chose the bald truth. I explained, in simple terms, what our interventions could and would probably do to Mrs. J. It was not an easy conversation. I did not say “what I would do”. Instead, I asked one simple question: what would she want? This question broke through June’s anxiety like a bucket of cold water. There was no hesitation in her voice, though her voice was small. She wouldn’t want any of this. With that single statement, I saw June change. She dabbed her eyes, asked me to get the physician, and signed the papers withdrawing care.

I stayed that night. I explained what the monitors showed, the changes and the final moments. I stayed and held June’s hand while she held her mother’s. I stayed to perform her final care. I don’t know if it made any difference for June, but I will forever remember Mrs. J and June, and the realization that there is more to what we do than what is written, and more that we can accomplish than what we first realize.

There is shared humanity in times of enormous change and the humbling experiences we live with our patients and their loved ones. I experienced death from my own perspective and that of a deeply invested family member. I was able to gain insight into the difference between extending life, in the most physical sense, and extending quality of life. I placed myself in the role of advocate, as a knowledgeable insider, to provide the full range of options for my patient. This was an extremely uncomfortable experience within the context of speaking up in the face of authority, but one from which I gained immeasurable confidence in my ability to provide for my patient. I have had many uncomfortable conversations over the years, both with colleagues and patients (and family members), but this experience with Mrs. J and June will always be my most powerful memory of experiencing death and finding my voice as an advocate.