

Waiting

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This story is based on a compilation of experiences, and details have been changed to protect privacy.

You're only a few years older than me, and today I'm finding it hard to be your doctor. Two weeks ago, everyone said you had days to live. Despite all the disease-directed therapy and the best efforts of multiple specialty teams, you are dying and none of us can stop it. And yet despite all the predictions here you are, holding steady even though you haven't had a transfusion in over a week. Your skin looks barely there, insubstantial like the clouds outside, yet with new hair sprouting in the bare patches. You've stopped waking up but your breaths are even, your pulses strong. There is no sign that you will die today. The nurses and medical teams are whispering in hallways with questions on their lips. "Did we make a mistake? Did we give up too soon?" It looked so dire, each day with worsening organ function and no signs of recovery, but now, over a week since we've checked your labs, you make us wonder. Should we check again? Was this premature?

The chaplain wonders if there's someone you haven't seen yet, a last goodbye that hasn't happened. Maybe that's it. Your parents were here, your spouse, your children ... but we start to ask gently, is there anyone who hasn't yet been able to see you? Your family looks at us incredulously and shakes their heads. We are stumped. It may be that we are bad at predicting timeframe, though usually we are overly optimistic, not the other way around.

Every day I slip into your room, quietly, to check in on whether your medications need adjusting. No sign of grimacing, except when the nurses turn you. They have taken to giving pain medications before any movement, just in case. Your breathing remains steady, your hands warm. There's a stuffed bear missing an eye in the corner, and I can't get the image of your young daughter out of my head, with the big yellow contact precautions gown dragging behind her on the floor. I feel the tears pricking behind my eyes as I think about how hopeful you were when you started treatment; mercifully, today your husband is not at bedside. He knows we tried, but it seems selfish to cry when he is trying to hold things together.

Just as I think I'm going to slip out undetected, your husband enters the room. The question mark is visible in his face. I ask, "How's today?" After what seems like a full sixty seconds, he responds, "She seems peaceful ... I've told her it's ok to go, that we'll be ok..." his voice crumbles here, and I can see him blinking back tears. "But she's ... the same. I've never seen anyone die before. Do you think we're missing something?"

I'm not sure what to say. Do I think you're waiting? Physiology doesn't seem to have an answer. We start to talk about what you two would do together before you got sick – hiking trips, seeking out adventures that made your families nervous, collecting as many passport stamps as the extended booklet would allow. After a few minutes he starts twirling his wedding band. He whispers, "We used to sleep curled up together every night. We haven't been able to do that since she's been in the hospital." He looks over at you and touches your hand.

I fumble, then ask if he'd want to get in bed with you now. His eyes widen. You look so fragile, and everyone has been telling him for weeks to be careful around all the lines and tubes. "Can I?" he asks. I pause. "Yes, the nurses can help us adjust things so you can get in bed with her. But... I'm not sure what to expect." He is looking only at you. "I really want to hold her."

I step out to notify the team of doctors and nurses what we're proposing. One seems uncertain, and asks, "But what if she stops breathing while we're in there?" I reply, "Then we step out and give him time with her." I admit I am worried about that too. We agree that giving them this moment together matters more than our fear, and we will go in together. The three of us take a breath and re-enter. Your husband is standing near you, touching your face, talking into your ear in a low voice. We silence the bed alarms, untangle the wires, and scoot you over a few inches so that there's space in the bed for two. He slides into the space, wraps his arms around you, and you pull in a single deep gasping breath. Everyone around the bed flinches. I see your nurse on the opposite side of the bed, her eyes flash wide, asking what to do. I motion silently and furiously (over your husband's back, hoping we do not take away from this moment) for us to exit, trying to both be calm and simultaneously gesture that we need to leave now. I tiptoe out, and one person follows – another is still lingering in the room. Should we go get them? We knew this could happen; we had a plan.

Two minutes later they step out also, looking relieved, and report that you finally breathed again. I gently ask why they stayed. They were worried about that breath having been your final moment, not wanting to leave if you had died moments after he took you in his arms. Yet that's exactly what happened. I will never know if that's what you were waiting for, but I like to think that you were hoping we could figure out how to create space for the two of you in an environment that actively separated you. How often do we prevent people from getting close to the people they love in the end because of tubes, lines, alarms, or hospital rules? There's something beautiful and necessary about reclaiming space in a hospital room for people to hold each other again.

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