When a Loved One Is Dying

I’m here again tonight where I often find myself: sitting in the dark beside Steve’s bed, not ready to sleep but not willing to leave him. Nights are both hard and good. They’re hard and then they’re good.

Around 10:30 every night, I give Steve his night meds—a pretty potent combination designed by hospice to help him sleep, keep him from choking and help with the pain he’s been experiencing in his shoulders. While they sink into his system, I refill the humidifier in his breathing machine, put his bed down, change the linens on his pillow and push the bed as far to the middle of the room as it will go. He rolls in 30 minutes later like clockwork and by this time, he can hardly keep his eyes from closing. I’m grateful for the meds that help him sleep more comfortably because sleep is his only escape.

I remove the neato cup holders from his wheelchair. His caregiver, Crystal, devised this ingenious system for him to keep a spitting-cup always within reach. He liked that so much that she added another one for the remote control. What man in this world wouldn’t want a carry-along caddy for his remote control? Crystal and Steve are partners-in-crime, for sure. At night, I take the cup holders off so he can move his footrest in which makes for a much safer transfer from chair to bed. How we discovered we needed a safer transfer system is a long, scary story that I’m not ready to retell just yet. (If you’ve never worked with someone with ALS, the best way I can describe it is to say it’s like moving someone whose limbs are made of heavy jello. It’s very awkward and I’ve yet to find a system that feels foolproof.)

With the footrest moved in, I take off Steve’s neck brace and shirt and then we count down to three and I lift him out of the wheelchair, balancing him on shaking legs. He can stand long enough to let me pivot him onto the bed. I breathe a

silent sigh of relief every time he is safely on the bed. He uses the suction machine and then I lift his head up from where it's fallen against his chest and put the breathing mask over his face. Nearly every time I do it, I wonder how many times I've done it in the past few years. I wonder how many times he has dreaded another night with the mask and how much he longs for the days when he could sleep without so many constraints.

I turn on the breathing machine and it makes a soft, whirring noise that has become a comfort to me. Steve lays down hard on the pillow—he has very little core control, so it's always a pretty ugly drop from sitting to laying on his side, legs dangling lifeless over the side of the bed. I lift his legs up and move his arms to an angle that is useful for him to gain some leverage.

I place a hand warmer in his palm, put his hands together and then wrap them in a towel. I cover him with several blankets and have learned to tuck them in well or he will wake me up soon, telling me he's cold. Nights are cold without muscles.

When he's finally lying there, tucked in and masked-up, we wait. I stand beside him while he decides what needs to happen with his head in order to be comfortable. He thinks about it for a bit (sometimes a pretty long bit, which is kind of annoying) and then tells me what to do. "Lift my head up and pull the pillow toward you." Things like that.

He's unable to shift his own head in any way, so he relies on others to do the adjusting for him. Sometimes I get it right pretty quickly, sometimes we'll go through seven or eight different positions before he feels ready to sleep. Not gonna lie, this is one of my more frustrating responsibilities.

When his head feels just right, he whispers, "OK. I love you." Every night, that's how it goes. And the process used to be repeated several times a night, but now it only happens once

or twice and, this week there were two nights when it didn't happen at all. He slept straight through from 11 to 9:00. That hasn't happened since … I can't even remember when. On the one hand, I'm glad he's able to sleep. On the other, I think it's indicative of the progression of this disease and how exhausted he always is.

Once we're in for the night, I pull the covers up over myself and my first thought is always, "We made it." We made it through another day. We earned a night of sleep. And we tried with all that remains to glorify God and to make His name famous. And maybe we failed a lot, but we tried.

Sometimes I fall asleep before any other thoughts, and sometimes I lay awake for long hours, thinking of how life is now and how it will be. I wonder how much longer our nights will be like this. If I'm honest, there's not a single night when I don't wonder if Steve will wake up in the morning. The longer we go, the more I'm able to shelve the stuff I can't solve, but sometimes it does race in all bossy-like, trying to steal my peace.

And nights like tonight, I write. I mostly write so that I'll remember it down the road. I write to remember these dark, intimate moments when marriage looked so different than I ever dreamed. I write for a day when I'll need to remember that I'm stronger than I think. And I write so the rest of the world can understand the brutal realities of life with ALS.

That's why I'm pushing publish on this post. Not so people will feel sorry for us, but so they will know the nature of the fight so many face, and that many of them face it alone or without the benefit of a caregiver who shows up in the morning. I believe that every person with working arms and legs has something they could give to a person who has none. Every person could volunteer time to give a caregiver a break or give some money to help find a cure. Maybe if enough of us tell our stories then we, the citizens of humanity, will be

compelled to fight for change.

I believe.