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The beautiful end

It was a usual Monday morning until the phone call rang in. The hospital wanted to send a terminally ill patient on life support to die at home. It is not every day that the hospice agency gets a request like this. On the surface it sounds simple, right? Set up the ambulance, transfer the patient home, and withdraw life support. That's it. A big goal of hospice is to allow people to die at home, but this was someone in the ICU, on BiPAP ventilation, and on pressors. After starting the planning process for her to go home that night, it became clear that it was going to take moving heaven and Earth to make this happen. And we did.

The woman was 47 years old. From the day she was born with a congenital heart defect, her parents were told she was not going to survive. She was born with one ventricle instead of two, and underwent innumerable operations through the years. What she did with her life was more than most would have done with her condition. She became a cardiac care nurse and worked with the same doctors that had cared for her, before she entered health care administration. She loved to garden and be social. She continued to outlive every short prognosis that the doctors always gave her, until now. Her heart could not hold out any longer and had

finally started to fail. After three weeks in the hospital, it became clear that this time, death was inevitable.

Her husband was not in denial and knew death was near. He also knew that her one final wish was to die at home, and that he was going to do everything in his power to make it happen. In the preceding week, he was preparing the room at home where she could rest during her final time. In his strong requests to bring her home, he was NOT going to take no for an answer. He would bring her home to die, if it was the last thing he ever did. Bound and determined, he convinced her hospital care team, who were understandably skeptical, to call hospice to arrange the transfer home for a terminal wean. After numerous phone calls with the many different parties involved (hospital, hospice, nursing, physicians, pharmacy, ambulance service, home equipment supplier), everything was set in place.

The doctor and hospice nurse arrived at the house at 6:30 p.m. in anticipation of her arrival. They went early to ensure that everything was ready. After all the planning, they had to make this work. They walked into the house and the sight took their breath away. It was a stately home with dark wood interior. French doors led into the

room that her husband had been preparing. White carpet. Huge windows. Dark wood crown molding. Large regal bed in the center of the room with the sheets turned down ready to receive her. Disney paraphernalia scattered all around (she loved Disney). Disney music playing in the background. A bouquet of 12 yellow roses on the nightstand. Her husband saw the looks on their faces as they scanned the room, and he said, "It's our anniversary today."

She arrived home around 8 p.m., and looked as blue as could be. The site of her made everyone wonder how she had survived the ride home, let alone the hospital stay up until now. She was taken into the room her husband had prepared with such careful detail. The drastic difference between her mangled physical condition and the beautiful surroundings was impressive. Her husband and sister helped the nurse put her favorite pajama top on and settle her into bed. Surprisingly, her eyes were open. She looked around the room but could not comment with the BiPAP face mask blowing fierce air into her lungs.

What happened next was a beautiful thing. Friends and family surrounded her bed, and her pastor conducted a prayer service. Her eyes were open

the whole time. Afterward, it was time for her husband to have some alone time with her. After all, it was their anniversary. Her eyes were still open despite her profoundly ill and rapidly deteriorating physical condition. She was medicated to help her breathing and the BiPAP mask was removed. He laid in bed with her, holding her in his embrace. They were looking into each other's eyes, and one could see through the French doors that she was actually talking to him. One can only imagine what they were saying to each other.

She died peacefully about two hours after arriving home while still in her husband's arms. Her husband seemed relieved that despite his loss, her suffering had come to an end. They had been at a holiday party together hardly six weeks prior. She had remained strong for so much longer than her doctors expected and through so much physical turmoil, but her eventual

decline was inescapable. He sat at the large wooden dinner table in the room next to hers and shared more about her life story, about how she had persevered through so much, and about how badly she wanted NOT to die in the hospital. The team eventually left the house speechless, pondering the beautiful end.

Author's note

Although research shows that the majority of Americans prefer to die in their own homes, nearly one-third of all deaths in the United States still occur in a hospital. The volume of inpatient hospital deaths is down 8 percent for the first decade of this millennium, according to the CDC, despite an 11 percent increase in hospital admissions.

Interestingly, the percentage of patients older than 65 has decreased, while the percentage of hospital deaths has INCREASED in the 45-64 age

range. This latter anomaly could possibly be explained by an increase in hospice use amongst Medicare decedents, as well as more life-prolonging technology available to younger chronically ill hospitalized patients.

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