

Hospice: What You Don't Know Can Hurt

by [jeastridge](#) @ [allnurses.com](#)

This is the story of one nurse's encounter with a family where she helps clear up some misconceptions about what hospice is and does.

I took a seat on the kitchen chair that the daughter brought in. Pulling it up to the double bed, I tried to get close to my patient, a woman nearing the end of her battle with gastric cancer. She tried to return my smile, and I squeezed her hand as I introduced myself. Her daughter circled around to sit on the bed beside her mom. She opened the conversation by saying, "Mom's been having a pretty rough day today. She is just so weak."



As we talked, I heard the bedroom door push open further. I recognized her son, Joe, from our brief introduction outside the house and nodded to him even as his sister continued to tell me about her mother's long battle with cancer. Easing past me, he took a position just behind me, standing against the wall with his arms crossed. He didn't say anything but I could feel some tension enter the room with him. When there was a pause in the conversation, I looked back and invited him to join our conversation by asking the question, "So have you ever had any experiences with hospice?"

He answered "No" and didn't elaborate further. I tried again, "I hope I can help you, your sister and your mom understand what hospice is and how we can serve your family." Emotion quavered in his voice as he said, "I'm not sure hospice is what we need."

I tried to assess whether or not to continue the conversation outside the room, but I could tell from his sister's exasperated sigh that this was familiar ground; they had fought this battle multiple times and the wounds were still fresh. He spit out the words, "All I know about hospice is that they give people drugs until they die." He stiffened his back against the wall, as if trying to hold the house together with his effort.

Consciously relaxing my body language, I turned to face him, offering him my full attention with open posture: palms up, feet on the floor, neutral expression. I reminded myself that he spoke with anger that disguised grief and loss. He spoke words pregnant with the fear of giving up his mother, of letting her down.

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About a Nurse



"Empty the Foley they said, it'll be easy they said!"

Thank You...

...nurses for guiding nursing students through clinicals.



Said a nurse...

"I felt shock, relief, horror and love all at one time."

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He told me about the diagnosis six months prior, followed by surgery, then chemo and complications. He said the doctor told them the treatments were no longer effective. His mom softly interjected, "Son, I heard that doctor say I don't have long left." He shook his head. I could tell he felt defeated. In his mind, accepting hospice would mean giving up, giving in.

This picture of conflicted emotions presents itself repeatedly in hospice settings. As professionals, we struggle to appropriately address the concerns people have about hospice. Each situation is different and requires sensitivity, creativity and discernment.

I paused before stating gently, "**Hospice doesn't do anything to shorten life or to prolong life.** We simply accompany people on their journeys and work to relieve troubling symptoms that might come up along the way such as pain, shortness of breath, restlessness, anxiety, etc." He turned to face me and I went on to explain as simply as I could some of the basic principles of pain management.

Our conversation rang a bell in my spirit that reminded me again of the sacred duty we have as professional hospice nurses with a powerful arsenal of medicines and interventions at our disposal. We have a lot of freedom in practice; we have earned the trust of medical professionals. Patients and families need to have the confidence that they are doing the right thing in how they use medication. A large part of this process is helping families have appropriate education and expectations of what can be accomplished. For example: complete pain control is a goal but sometimes cannot be accomplished without excessive sedation so we must work together to figure out what is important to the patient. Helping all team members understand the plan and its implementation can help to eliminate conflict for even the appearance of over-medication threatens the confidence and trust we all value.

Mindful of the import of what I was telling this family, I reinforced the teaching about our 24-hour availability. "Call us any time," I told them. "That is what we are here for. And if you need us to come out, even in the middle of the night, we will do that, too." Being available and willing to respond to families' needs goes to the true heart of hospice nursing. For we cannot simply teach them, check it off, and then expect perfect comprehension. Having that phone number is gold. It helps sooth frazzled nerves, allay mental fatigue and overcome simple ignorance of bodily processes.

We took a break from our conversation to notice the cat that jumped up on the bed, purring and settling itself neatly beside the patient's hip. We all laughed a bit and the patient reached over to rub the cat's neck. The daughter spoke next and said, "What I think bothers Joe the most is giving up. We have been trying so hard. We have done everything right. Why isn't it working?"

I stopped cleaning my stethoscope and held it quietly in my hand as I told her, "**Hospice is not about giving up. It is about changing goals.** Signing up for hospice care indicates a change in focus-almost an "about face"-looking toward quality vs. quantity of life. It means that we continue to do plenty, but just different things than we do when pursuing life-extending therapies." She and her brother nodded that they understood and I continued to explain more fully, "While chemo, radiation, transfusions are rarely on the list of considered therapies during hospice care, there are times when they do fit because they help address comfort care needs. Also, at times a few of our patients improve temporarily as the complications associated with treatments ease. Sometimes there appears to be a sense of psychological relief after the decision for hospice is made. We always retain the knowledge that there is an opportunity for a miracle. Being in hospice does that mean that a patient cannot be healed. Occasionally, some patients live on and are discharged by hospice as their condition improves."

Joe walked around the bed and as his sister scooted over, he joined her sitting beside his mom. Taking her hand he said, "I just want to be clear that we will only do what mom wants. We don't want you all telling us what to do." His change in posture and position told me that he had really entered our conversation but his words communicated his strong sense of protectiveness toward his mom and a long tradition of fierce independence.

I acknowledged his words with a nod and noticed his mom indicating she wanted a drink. I reached over for the sweating glass of ice water that rested on the beside table, and adjusting the straw, offered her a sip.

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"You are so right, Joe. **The patient and the family remain in control.** We are here to serve your mom and your family and to advocate with the other treatment partners. We will try to listen carefully and follow your mom's desires. Each person faces death on their own terms."

"Ok. So what if we decide to sign up today and then change our minds?" Joe lobbed his final volley across the bed with force and conviction, as if daring me to answer. I smiled as I answered, "**It is possible to revoke hospice.** It is important for patients and families to understand that hospice is not always the correct option. Even with the paperwork signed, there is no permanent commitment. You all can change your mind if a new therapy becomes available or if you simply decide you are not ready."

"I want to rest now." Their mom dismissed us with a gentle wave of her hand. I quickly finished up my assessment, and we shuffled out toward the kitchen. Leaving last, Joe flipped off the overhead light and blew a kiss into the dim room.

Joy Eastridge