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The Case Manager's View

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Case management at our hospital was designed, from its conception, as a patient-focused program with goals to improve patients' satisfaction, decrease length of stay, and decrease overall costs. I never found myself at odds with this philosophy until the year I was the case manager for Lorraine.

Lorraine was admitted in May 2004. Her primary care physician, who was overburdened and frustrated by Lorraine's constant paging and calling, admitted her in the hope that a last effort at wound management and pain management would be successful.

I knew Lorraine from an admission the year before. She'd been admitted then with similar issues and signed herself out "against medical advice" after several days. As a result of that admission, I was aware of several problems that would be barriers to ultimately discharging Lorraine.

First, she had a long history of substance abuse and noncompliance with any medical plan. Lorraine had been discharged from services from several homecare agencies because of her behavior. Also, she lived with a significant other who was not available to assist with any of her care. Her closest living relatives, although supportive and involved, were unable to provide physical support. On admission Lorraine clearly informed the healthcare team that she would not consider being discharged to a skilled nursing facility. She was knowledgeable regarding Medicaid and disability benefits. Although these things would make discharge difficult, the greatest challenge to me, as well as the care team, was to formulate a clinical plan and engage Lorraine's participation and agreement with it. Throughout Lorraine's stay, all of the skills and talents that are typically identified with case management were put to the test: accessing resources (MassHealth, community providers, discharge experts), negotiating with the patient and potential caregivers, collaborating with multiple caregivers on a daily basis, and, most importantly, advocating for the patient.

Case managers frequently ask questions of others and ourselves about ethics — questions about the decisions we make and the paths we follow as we try to find people and places to continue caring for the patient. Before and after Lorraine decided to withdraw from any further medical treatment, I struggled with her unwillingness to follow a medical plan that could make a difference for her well-being and the quality of her life. I had great difficulty with my urge to push Lorraine to follow the plan that we, the care team, knew was best for her. In plain words, I wanted to control the process. I was frustrated with her unwillingness to understand that home was not an option because she required too much care and was not considered trustworthy. At times I was stunned by the anger I felt toward her because she had done nothing, that I could see, to keep herself from ending up in this spot and because she would not help us to help her. It was in those moments that I was reminded of the importance of the care team; for at each hurdle that each of us faced during her stay, the support and guidance from our fellow team members ultimately made the difference for Lorraine and ensured that her wishes and decisions were respected.

My plan was to support Lorraine's plan. She wanted to die at home or at the hospital. Unfortunately

there were no resources or agencies in the community that were able to support a transfer home. Over time it became clearer and clearer that Lorraine would die in our hospital. I found those months leading up to her death difficult. I frequently experienced a sense of failure, a sadness that I had been unable to "make it happen" for her. I had referred Lorraine to approximately 40 skilled nursing facilities/acute rehabs, in-patient hospice, several home health agencies, and hospice programs. Several times, especially as the holidays came closer, other members of the team would ask me, if I was able to, would I send Lorraine out before Christmas.

Lorraine died on the weekend just before Christmas. When I arrived on Monday morning and noted her name was no longer on the census, I felt an emptiness that I had not expected. This woman, who had such difficulty with trust, had developed a bond with us. When she died at night, she was not alone. Two of the nurses who had cared for her over the many months of her stay were with her, holding her hand as she slipped away.

It wasn't until I went to her wake, and then had a chance much later to speak with her mother and sister, that it became clear to me the difference we all had made for Lorraine and her family. The plan had worked.