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## Talking with Lorraine's Mother and Sister, Five Months after Her Death

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Georgia, Lorraine's mother, and Denise, her sister, shared their experiences as Lorraine's closest family members in an interview five months after her death. We sought to learn about what it was like for them to live through Lorraine's final hospitalization, as well as their reflections on Lorraine's life.

Georgia shared the goodness in Lorraine, describing how her daughter had cared about others. As a teenager, Lorraine had given multiple hours of volunteer service to the patients at Tewksbury Hospital. She loved to hold yard sales to raise money for this and other causes. She was filled with goodness as a child.

Georgia then shared some of the pains that Lorraine experienced during her life. She and Denise expressed regret over a "life lost," a "life that could have been different."

Lorraine's father moved to California after her parents divorced, and he remarried. Lorraine, at the age of 14, wanted to spend a summer with him, and made plans to do so. But as the time for Lorraine to travel to California to visit with her father grew closer, he rejected these plans, and she learned she was not welcome to come and stay. Georgia believes that this news took an emotional toll. It seemed that, from that point forward, Lorraine was "off and running."

Georgia worried terribly about Lorraine throughout her teens and early twenties, and described how, after Lorraine had been involved with drugs for some time, she came home, so sick, and simply lay in bed. Georgia's husband wanted to call an ambulance, and initially Georgia resisted, saying, "No, at least she'll die in a clean bed." Upon hospitalization, Lorraine was found to have bacterial endocarditis.

Both Georgia and Denise loved Lorraine, and, through all of her difficult behavior and the walls that she had built around herself, they remembered her goodness and childhood smile.

Both spoke of their experiences and stresses in being Lorraine's caregivers at her home. They spoke of how Lorraine valued being on her own. Denise said, "Home was very important to Lorraine. She used to like to get up in the morning and cook, and she liked to go shopping, and she was very independent." Prior to her final admission to the hospital, Lorraine had started to lose home medical services. This was very stressful for Georgia and Denise, as they worried about her, and knew that her behavior played at least a partial role in the loss of these services. Even then, when Lorraine was admitted to the hospital for what turned out to be her final admission, they did not believe it would be any more than one of her routine hospital admissions. Georgia remembered, "She was losing services, the way everyone was losing services across the board. Going to the hospital was something that we had been used to; it was kind of a cycle, going in for treatment

and coming back. Lorraine thought that perhaps she could get some increased services" through being admitted to the hospital.

Denise went on to say, "So we did not see her admission as anything unusual. It was just the visiting nurses having her come in for one week. We didn't realize she was as sick as she was." She continued, "When Lorraine was in the hospital, I was able to change roles and just be her sister. Because she had all the caregivers that she required, I could just be her sister and just care about her. That was very important to me."

There were a few times during her last hospitalization that Lorraine had wanted to go home, and actually demanded to be allowed to do so. Denise recalled, "She had this big thing about home. Like, I ended up coming at 4 a.m. one morning because she was on the phone and saying, 'I want to go home,' and being a real pain in the neck. And I said, 'I talked to the hospital, and we can have you home in the morning.' She turned a corner when it became real, and she didn't want to go. She said, 'No, I don't want that,' and she fell asleep, and that was a good thing. I told her that she was being a pain in the ass — excuse me — but she was. She just needed somebody to say yes or no, be a little bit more real with her. So when it became real, she didn't want to go. She knew she was safe here."

Hospitalization was difficult for Lorraine because it placed limits on her behavior. Georgia said, "She had a lot of self-interest. She didn't really think about how it impacted you. She thought about herself and how it impacted her. She was a social monster. She needed to get downstairs. She needed to smoke a cigarette. I remember the first time when she was restricted to bed. She took it so hard. It's like being grounded. She was not listening to anything. It's one thing to refuse medical advice, but when she wouldn't take any advice and wouldn't listen to anything. . . ."

When discharge from Lorraine's final hospitalization was being considered, Georgia and Denise expressed their fears about how they might not be able to compensate in providing her home care, as services were increasingly being denied, due to Lorraine's past noncompliance and behavioral issues. A plan to discharge Lorraine to home was then abandoned by her professional caregivers, in part because of the toll it would take on her mother and sister.

Denise said, "She stopped saying that she wanted to go home." Georgia added, "She had a difficult time. When she found out that they couldn't fix her hip and that things had gone too far, handling dressings and that type of thing, it was sort of like chemotherapy when you're too far gone. She said, 'There's nothing else they can do for me.' "

Denise believed that Lorraine had confided in her about limiting life-sustaining treatment, and Denise kept this to herself so as not to hurt Georgia, who at that time could not conceive of giving up. As time went on, Georgia came to realize, with the help of the nurse practitioner, and from what she was observing, that Lorraine was not going to get better. Georgia noted, "She lost all the muscle tone in her leg, and it began to atrophy. Things like that. On her last day, if I had known she would have gone that night, I would [have said to myself], 'Don't go home now, stay a couple more hours.' [To be there when Lorraine died.] She smiled at me, and I told her, 'It's okay, Lorraine, you can leave.' She was like a little girl at that point, with a peaceful, sweet, angelic smile."

Georgia said that she wishes she had not left that night, and wishes that someone had said, " 'Stay with her, she is going to die.' " But Georgia also said she knows that this is not possible even for professionals to predict. She repeated, "I will always remember her smile, like a little girl's smile, she looked so peaceful."

Denise, who had come in after Lorraine had died, expressed it this way: "On the day that Lorraine died, she seemed to be so peaceful, like they had the symphony orchestra there the day that she passed away. She was surrounded by caring people. It was perfect, even the gravestone." Denise shared that she was so impressed by the post mortem care: "Lorraine looked so peaceful, clean, and warm, with her purple monkey."

Their comments in the interview are summarized by their description of how Lorraine was cared for during her final extended hospital stay. They believe that Lorraine felt the compassion of physicians, nurses, and therapists — and her family felt it as well. In a final comment, Georgia said, supported by Denise, "The last six months of her life [while she was hospitalized] were one of the best times for her in her life — she felt safe and cared about."