

### **Julie's Advance Planning**

I was once sitting with a fourteen- year- old, Julie, who had shown little recognition of the seriousness of her condition despite two relapses and a stem cell transplant when I got a call from her doctor to tell me she had relapsed again and no more curative treatment remained. My face must have showed my feelings because Julie said, “That was Dr. \_\_\_\_\_ , wasn't it, and he said I've relapsed,” and she burst into tears. I asked her if she had suspected it, and she told me she had been talking with her boyfriend the previous night and had told him she thought she had relapsed. We were then able to go on and talk about the choices she still had and, sadly, the choices she no longer had. Julie was able to plan specific goals for herself, including:

- To be in her brother's wedding.
- To be at home as much as she could be.
- To be as comfortable as possible.
- To see her friends and her boyfriend as much as possible.
- To come and see us sometimes.

Julie was then able to tell her doctor and her parents what we had come up with— and her endoflife care was designed to see she met as many of those goals as possible. She visited the clinic with her mother two days before she died. She harassed her doctor whom she loved dearly for keeping her waiting. I gave her a card to take home with her which I read to her to tell her how much she had meant to me. She told us how she was comforted by praying with her mother for herself and for others worse off than she was, how her schoolmates were dedicating the endofyear concert to her, how she held a smooth stone and stroked it to calm herself. Her doctor and I went with her to the parking lot where we hugged her and said good- bye. Julie died peacefully in her sleep two nights later at home. Her mother— a woman of immense strength and faith— said, “I did not know death could be beautiful.”

### **Jenn's Last- Minute Acknowledgment**

Jenn, a lovely, courageous, and vibrant adolescent aged fourteen, had relapsed after a difficult and complicated treatment. Till that point Jenn had attended every medical meeting with her parents and had been a primary decision maker in matters relating to her treatment. She and her parents were told by her medical team that she had relapsed and there was no curative treatment. Jenn was enraged and extremely upset. She ordered her oncologist to explore more treatment options. She stated she was “not ready to die” and was not going to die. She subsequently refused to talk with her oncologist about her Do Not Resuscitate (DNR) status or her declining health. Jenn's parents seemed uncomfortable having discussions with the medical team without Jenn present. The medical team wanted to honor Jenn's wishes and admired her spirit, but they thought it was in her best interest that some decisions be thought about in advance of a medical crisis— particularly since the family lived a long way from the clinic. Her parents did discuss options for endoflife treatment and DNR status. They knew Jenn wanted to be at home, not in the hospital, and opted for caring for her at home. They had to get some medical support locally.

In her parents' words:

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It felt awful. It was not what we were used to. It felt we were sneaking behind her back. But we had to. Despite Jenn's objections, we had to call the local hospice, as the local visiting nurse association was not comfortable working with an adolescent who was that sick. Jenn told the first hospice nurse who came, "If you come here, I don't want any of that cloak- and- dagger routine." But the nurse thought we were all in denial (which we were not) and felt she needed to step in and talk with Jenn— told her she was being selfish and making things difficult! When we found out, we fired her. She just did not understand what Jenn needed. The next nurse who came was wonderful. She supported all of us and knew how to talk with Jenn. She helped us feel safe. Jenn did tell us after one of her radiation treatments that she had known in her heart from the beginning that she would not make it. But the rest of the time she (and we) wanted to keep it as positive as possible.

I was allowed to visit Jenn on her birthday provided I agreed not to discuss her condition with her! I instead gave her a birthday card that listed some of her many accomplishments— noting that most people would not accomplish in their lives as much as she had already accomplished. The night before Jenn died, the family acknowledged to one another and with Jenn that she was dying, how sad they were, how much they loved her, and how she would continue to be part of their lives. They called their priest and Jenn was able to tell him about the funeral she wanted.

In her mother's words, "The priest came and gave her the last rites . . . Jenn had good friends in school who were in a band. She told the priest she did not want a 'fuddy-duddy funeral' and she wanted her friends to play her favorite music at it. He agreed and they played."

### **Mark's Minimum Acknowledgment**

An eighteen-year-old young man, Mark, was adamant that he would live despite the odds. He had a terrible prognosis. He made it through his first stem cell transplant and managed to get to his high school graduation. He was determined to go to college. He was accepted and began attending. He relapsed and persuaded his doctors to consider a second transplant, which was highly unusual at that time. His father remarked to me at this point that he appeared stuck in denial. However, around this time Mark said to me: "I don't think my doctor realizes I understand what my prognosis is— that I have one chance in a thousand of surviving, but I am choosing to focus on that one chance." He got through his second transplant and read up on courses he wanted to take the next semester. He was eagerly planning to return to college when he relapsed again and was admitted to the hospital in critical condition. When I visited him, he asked the other people in the room to leave. I assumed he wanted to speak about his imminent death. Instead he told me he was having trouble with his attitude and his ability to continue to think positively. I told him that everyone needed to give themselves a break sometimes. He died a few hours later.

### **Brian's Selective Acknowledgment**

Brian was sixteen years old, the youngest of four children who lived with his parents and siblings. He had relapsed and had a poor prognosis. He was a fine student and athlete, much loved at home and popular in school. He was a resourceful, thoughtful, and caring young man who was having considerable pain from his treatment and his disease progression. He was referred to me to see if hypnosis would be helpful. It turned out he was already using a form of self- hypnosis that was extremely helpful in managing his pain, and he needed little additional help from me. I spent more time with his parents, who were suffering terribly because of his deteriorating and terminal condition. Neither felt they could discuss it with Brian because they said it would be too painful for everyone. They also thought that he was unaware of how seriously ill he was. One day he became very ill at home and told his sister who was

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there that he knew he was dying and he would like her to call the priest and get in touch with his parents at work. He also told her he had been talking about dying with his friends. They spent the rest of the day talking with each other about many things, including how things would be in the family after he died. His parents came home, and they and the priest were all there when he died. His mother asked his sister three months later whether Brian had known he was dying and if they had talked together about it. She was very relieved to hear that he had had someone to talk to.