

Without Regret

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ABSTRACT

The mother of a child with a very rare, severe genetic condition that affects many body systems writes about the importance of respectful, honest, empathic communication with the care team.

Our first child began to show abnormalities not far into my pregnancy. In her first year of life, one symptom after another began to appear. We had a grocery list of specialists, including three geneticists, yet we still did not have a diagnosis. Finally, at three years old, she was diagnosed with Schinzel-Giedion syndrome, which carries a life expectancy of two and a half years.¹

Our care team continued to grow at a steady pace. Meeting and orienting hospital and clinic professionals, as well as home care staff, to our daughter and her needs became a constant practice, and one at which I became quite skilled. A successful relationship with our team was 100 percent dependent on effective and respectful communication. We learned that, although our care teams were the experts in medicine, we were the experts on our daugh-

ter. Professionals who did not grasp this concept or respect it were dismissed. Our daughter's quality of life and the care she received were always the number one priority.

Most of the physicians and staff we encountered respected our wishes, listened to our concerns, and valued our input. The best example was the relationship we had with our daughter's palliative physician. Over the years we had countless conversations that resulted in improved care for her and quality of life for our entire family. One of the most difficult conversations came after two serious illnesses resulted in sepsis,² and she nearly died. We had to accept that something undeniable had changed and that it was time to discuss hospice. With the most incredible sincerity and honesty, we shared an intimate conversation with this physician about her prognosis and the new, terrifying boundaries we would have to live within.

During the year and a half our daughter lived on hospice, many situations arose where she required some sort of intervention to manage ever-changing distressing symptoms, some of which resulted in surgical options. While her palliative doctor voiced concern for our daughter's ability to survive a surgical procedure, he also allowed us the space to make our case for surgical repair and share our strong feelings that our daughter's increasingly painful condi-

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tion was not the quality of life she deserved. The palliative doctor not only heard us, he stood behind us and helped us to make arrangements for the surgery. Unfortunately, one week before the scheduled procedure, our daughter took another turn for the worse, and we all agreed to postpone surgery indefinitely. It was a heartbreaking conversation to have, but it was handled with compassion and empathy that I will not forget.

Our sweet girl died less than a month after that conversation, at seven and a half years old. My husband and I were able to face her death without regret because our supporting physician cared enough to honor our need to know we had given her every chance to have the best quality of life possible.

Respectful, honest, empathic communication from a care team can make a profound difference in the lives of patients and their families. Our experience with her palliative physician is evidence of that.

NOTES

1. According to the National Institutes of Health, "Genetics Home Reference," "Schinzel-Giedion syndrome is a severe condition that is apparent at birth and affects many body systems. Signs and symptoms of this condition include distinctive facial features, neurological problems, and organ and bone abnormalities. Because of their serious health problems, most affected individuals do not survive past childhood."

U.S. National Institutes of Health, "Genetics Home Reference, Schinzel-Giedion syndrome": October 2018, <https://ghr.nlm.nih.gov/condition/schinzel-giedion-syndrome#synonyms>.

2. Sepsis is a serious illness that happens when the body has an overwhelming immune response to a bacterial infection.