

Making Meaning After the Death of a Child

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KEYWORDS

- Pediatric palliative care • Bereavement • Patient experience • Medical storytelling
- Medical education • Patient voice

KEY POINTS

- Two bereaved mothers articulate how they made meaning after the deaths of their children.
- Opportunities to share their experiences in medical settings helped them construct narratives of resilience and a sense of control.
- Pediatric palliative care can be conceived of as a way to provide space for patients and parents to tell their stories outside of the specifics of illness, thereby initiating the process of meaning making.
- Viewing video interviews of parents of children with serious illnesses allows medical trainees to understand the parent perspective and hear their stories, enhancing trainees' communications skills, empathy and compassion.

INTRODUCTION

This article is a story of stories. It begins as 2 individual stories, as told by Blyth and Sandy, about caring for children with rare and life-limiting illnesses. These paths then join together to become a third story that, as it unfolds, gathers up the stories of many other families. All of the families and their stories are different in the ways that families differ, but the essential subjects and themes are similar and formidable: the life and death of a beloved child from serious illness, the quiet thirst for meaning that follows, and the gradual construction of that meaning over time.

Making meaning is a universal human endeavor, but for a parent whose child has died, the enterprise takes on urgency and focus. Sandy and Blyth were finding meaning in nurturing their children and looking forward to the normal milestones all parents anticipate. With the radical disruption of losing their young children, every aspect of

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their lives changed and the excruciating questions arose: Is there a meaning to my life now or is there different meaning to my life, now that my child has died? And if so, what is it?

For both women, the journey toward reconstructing meaning began with the simple impulse to tell the story of what happened, sharing with medical providers and other parents who had experienced the death of a child. Their efforts have resulted in a profound friendship borne of shared experience, collaboration around advocacy for pediatric palliative care, and innovative work in medical education. The culmination of both their journeys is the belief that it is through story that all parents can find their meaning, along with growth, resilience, self-compassion, and a sense of control.

BLYTH LORD'S STORY

"The world was broken and the three of us—mother, father, son—were falling into its mouth." This line from Emily Rapp's grief memoir *The Still Point of the Turning World*,¹ written in the first year after she learns that her infant son has Tay-Sachs and will die sometime in the next few years, resonates so completely with me because it was exactly how I felt when I learned that my second daughter, Cameron, had Tay-Sachs. Except in our case the line would read, The 7 of us were falling into its mouth, that is, 2 fathers, 2 mothers, the 2 children, and 1 sibling.

In 1999 my 18-month-old nephew Hayden was diagnosed with infantile Tay-Sachs. One month later, my 6-month-old daughter Cameron was diagnosed with the same disease. Tay-Sachs is a rare and incurable genetic illness that always ends in early childhood death. Both parents must be carriers of the gene. Hayden and Cameron's fathers are identical twins, unknowing carriers who both married unknowing carriers—women who were best friends in college. The twins' genetic mutation had never been seen before, and the likelihood of these two brothers marrying carriers and having affected children was 1 in 80,000,000. What happened in our family was a statistical near impossibility.

But, in its way, it made everything that followed possible.

My husband Charlie and I and our brother and sister-in-law, Tim and Alison, were traveling together on the road toward our respective children's deaths. We were also traveling the distance together to figure out how to cope. Our children would be beloved. We would give them the best lives possible and then prepare to give them the best deaths possible. And we would pray that we survived.

We did more than survive. Despite the profound sadness of watching our beautiful daughter lose all cognitive and physical abilities, Charlie and I were able to live fully into Cameron's short life and to help Cameron's big sister Taylor, 4 years old, understand it as best she could. Despite the fear we had of losing Cameron, we became prepared to accept, face, and allow her pending death. Shortly after Cameron's diagnosis, Charlie bravely declared that Cameron's life would have a full arc, with a beginning and a middle and an end. We would do the best we could to live into that arc and to make the ending a good one.

I give much credit to the gifted psychologist, serving as a grief counselor with whom we worked during Cameron's life, for our ability to construct and own this vision of an arc to the point where it felt like destiny. She shepherded us as we processed our anticipatory grief following the diagnosis, and she helped us begin to put the pieces together so that Cameron's death was not a tragedy that was happening to our family. Rather, she helped us look at the experience in all of its facets, matching the sadness with the joy and the loss with the personal growth that we could feel happening even in her office. If I had to tell you where the tone was set for our story, I would say it was set

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