

## LESSONS FROM A BEREAVED MOTHER AND A BEREAVED SIBLING

**Oralea Marquardt, MSW, LCSW**

William's mother

Licensed Clinical Social Worker

Treasure Coast Hospice

Ft. Pierce, FL

[OMarquardt@treasurehealth.org](mailto:OMarquardt@treasurehealth.org)

and

**Kyla Marquardt**

William's sister

On January 9, 2007, my second child, William, was diagnosed at the age of 18 months with an ultra-rare neurodegenerative disease, Gm1 gangliosidosis. There is no cure or treatment option for Gm1 and most children diagnosed with the infantile form of the disease die by the age of four. Our family enrolled William into hospice care at the age of two and, with the care provided, he was able to remain at home and outlived the prognosis of his disease. William died surrounded by family on February 13, 2014. He was eight years old.

My oldest daughter, Kyla, was five at the time of diagnosis and was thirteen days shy of her twelfth birthday at the time of William's death. The impact of William's illness and death on Kyla was always one of my chief concerns as a mom. My experience led me to becoming a Licensed Clinical Social Worker. I now work in the field of pediatric palliative and hospice care and am passionate about supporting siblings of our pediatric patients. Since William's death, Kyla and I have ongoing conversations about the sibling experience to enhance the work that I do. Kyla has become an advocate in her own right, sharing her story at conferences and through various platforms with the hope that it will increase knowledge of the sibling experience and will help other siblings of children diagnosed with life-limiting conditions.

Recently, I sat down with Kyla, who is now nineteen and enrolled in her second year of Chemical Engineering at the University of Florida, and we reflected on the years caring for William, his death, and the grief that followed. Our conversation focused on three key elements: the impact of William's illness on each of us individually and as a family; support we found and what helped; and how our wellbeing and relationships changed in meaningful ways.

### **Diagnosis Day and the Aftermath**

I vividly recall my sweet little boy playing happily on my lap while a geneticist informed us that he would slowly lose his abilities, one-by-one, and ultimately die. Each moment of the fateful day that our family now refers to as "D-Day" is etched in my memory. My husband and I drove

the two hours home from the doctor's appointment in silence. My mind was in a fog, yet at the same time consumed with questions and thoughts. How was I to care for him? How would I know what to do and if he was comfortable? This was not how I imagined our life to be. My heart was breaking. As we arrived home, we were immediately greeted with a big hug by our 5-year-old daughter, Kyla. My immediate thought went to her wellbeing. How were we going to tell her that the brother whom she adored was going to die? How could we support her while dealing with our own grief? I wanted with all my soul to protect her from the hurt that would accompany the pending losses. My heart broke once again.

In the months that followed, I was consumed with navigating a complex medical system, specialists' appointments, and learning more about Gm1. At the same time, William's caregiving needs were increasing, and he was not sleeping. My husband and I were working in shifts to care for him while simultaneously trying to keep life as "normal" as possible for Kyla. Eventually, we contacted our local hospice agency for help. The hospice team embraced our family and for the first time since we received the diagnosis, we felt hope. The hospice team guided us in developing our philosophy of care and assisted us in addressing William's ever-changing physical needs. There was a sense of relief that we were no longer doing this alone.

Kyla's experience was much different. This is what she remembers most:

I cannot recall the details of when I learned about William's diagnosis and prognosis, but Gm1 became a common word in my day-to-day life. I knew that William was different from my friends' siblings. I was aware that Gm1 would cause my brother to die, yet it was hard to really comprehend. What I truly remember was the feelings I felt as William's disease progressed.

My biggest struggle when William was alive was the feeling of loneliness. Our house was in constant motion with nurses, social workers, and chaplains. While the nurses and my mom were almost always at home, they were often busy with William, and I did not want to disturb them while they had bigger issues. I also struggled with making friends as I had trouble relating to kids my age who had "normal" childhoods. I spent much of my childhood entertaining myself.

### **Finding Support**

Along with addressing the medical needs of William, hospice provided a volunteer to sit with him so that my husband and I could leave the home and solely devote our attention to Kyla. They also provided counseling to attend to our anticipatory grief needs. The counselor that my husband and I met with gave us the space to express and process our feelings. She also gave us guidance on the language to use to talk to Kyla about her brother's illness and offered strategies to support her. Kyla met individually with her own counselor. I was thankful she had someone outside of the family system who could help her process her own feelings as I was worried that she was hiding her feelings from us.

After a while, Kyla began to express that she did not want to continue with counseling. I was adamant that she continue because I found it so very helpful for myself. My counselor advised me to let Kyla take the lead of what she needed and to give her an element of control in a situation where she had none. She also alerted me to behaviors that may present that would indicate a need for counseling to resume. It was tough for me to take this advice, but I did, and through Kyla's recollection of that time, I now recognize the importance of doing so.

I was five when I entered counseling with hospice. Looking back, I can appreciate how the counseling laid the foundations of asking for help and expressing my feelings. However, as time progressed, I grew tired of talking about William and my experience connected to him. I wanted to be recognized for who I was, individually, and not have my identity to be only as the sister to William. It was my hobbies and my parents' support of my hobbies that helped me the most while William was alive. Music, martial arts, and even school were all endeavors that gave me the spotlight, and successes that my family could praise me for. I enjoyed constantly focusing on the tangible and being able to improve myself and my skills.

### **Growing with Grief**

After William's death, I continued counseling and immersed myself with patient advocacy activities. Kyla stated she did not want counseling or to continue with the fundraising and awareness events that she initiated while William was alive. Again, my instinct was to force her to do both because I found both were helpful to me as I grieved. However, I remembered the advice to empower Kyla with choices. I recognized the importance of allowing Kyla to find her voice and develop her own narrative of her experience.

Meanwhile, Kyla turned to the activities that she began while William was alive to cope with her grief.

When my brother died, it was my music that helped me cope. I was able to stop focusing on the eerie silence that now permeated my house, instead filling it with the melodies of my choice. I fell in love with repainting the world around me in sound, to be able to lose myself in the universe for even just a few moments. I carried myself with a new purpose that has stayed with me throughout the rest of my life.

When Kyla turned fifteen, she began to talk more about William and was ready to return to counseling to process her grief and share her experience with me. I will be honest; the narrative of Kyla's lived experience was sometimes hard for me to hear because it brought to the surface how much she had endured. In supporting Kyla in her grief, I had to be vulnerable, be willing to examine how I parented her, and acknowledge the times while she was growing up where I was not emotionally present to attend to her needs. As hard as these difficult conversations were, I knew they were essential and a pathway forward in our healing as a family. I believe that our family's bond is stronger because we learned how to communicate with one another. Learning how to acknowledge and validate each other's feelings and having open, honest, and difficult

conversations continue to serve us time and time again as new challenges in life occur. I like to think of this growth as a gift from William. Kyla defines William's gift to her in this way:

It is hard to tell exactly how my life was changed by William because he was such a core part of my childhood. His life impacted mine in almost every way imaginable. I feel that I have grown up to be a more empathic and compassionate person because of my experience. In teaching me the power of music, William taught me the value of living with passion, of focusing on personal development, and of occasionally surrendering myself to serenity. The most important thing William taught me was personal resilience. William, for whom every day was a struggle, showed me that humans can endure so much more than we may initially perceive possible. His ever-persisting smile and happy glow are some of the strongest memories I have of who he truly was, and despite everything, he never failed to make us laugh. Growing up with a brother like William made me realize that no matter how bad the circumstances, I have strengths and resources that allow me to get through times of adversity.

-###-