The Family Voice

Transparency Conversations that Build Strong Partnerships

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ABSTRACT

A mother writes about the experience of learning her daughter has a nontreatable brain tumor. She describes the impact of open communication among all of the parties involved. This transparency and communication aided the family through their journey, establishing trust between the family and team. The author describes how important this was, especially during the last six months of her daughter's life.

Our youngest child was diagnosed with diffuse intrinsic pontine glioma (DIPG), a rare non-operable and nontreatable brain tumor, at the age of one. The diagnosis came after magnetic resonance imaging (MRI) for what we thought would confirm Bell's palsy, due to signs of left-sided partial paralysis, resembling that of a stroke victim, after completing treatment for strep and scarlet fever. Upon diagnosis, we were thrust into a whirlwind of procedures, processes, and an unknown world with a very grim prognosis.

Our primary care team consisted of a very large group of healthcare professionals in the clinic, at the hospital, and at home. Our team, overall, consisted of oncology, neurology, neurosurgery, palliative care, research hospitals, social work, child life, physical therapy, and psychology. In general, all communication went to all individuals, always. As soon as we found out our child had a brain tumor, I told our oncologist that I wanted to be involved as much as possible and that I didn't want anyone to hide anything from us. Our oncologist encouraged us to be as involved as we wanted. Our team explained to us on several occasions that we are the parents, and we know our child best. This encouraged us to always be open and honest in our questions, concerns, ideas, and even our deepest fears. Our child's needs were incredibly complex due to the type of tumor and outcomes she was facing.

The success of our large team was completely dependent on the ongoing, inclusive, and transparent communication we asked for, from the beginning. This meant learning how to ask for clarification on terminology, asking for help, and learning to voice concerns. In terms of the team, it meant asking us questions to learn about our child's character, likes, dislikes, or simply following up on how a recent trip or first day of preschool went.

Our first two years of the journey were spent in surgery, completing standard treatment and trial treatment protocols, along with therapies, and traveling across the United States regularly. Our last year of medical care was spent learning how to gain compassionate-use authorizations and off-label trials through big pharmaceutical companies, receiving palliative care regularly and treatments that had the

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Amanda Bekric writes about the relationship she and her family received from the members of their daughter's medical team.

least amount of side-effects once our daughter's tumor had grown to a point that we could no longer participate in trials.

During the last six months of our daughter's life, there was one conversation that occurred that remains a vivid memory for me. I was on my way home from work. As I drove along the river, big snowflakes were falling as I peered at the orange glow from the lights that lined the street. I had a call with our daughter's oncologist. I had to tell her something I had been trying to avoid since day one of our daughter's journey. I remember the pain, sadness, guilt, and vulnerability in saying, "I know [our daughter] is dying, but I want to do everything in my power to never give up on her, and always push forward. Our team needs to remind me to pick quality over quantity, and when she passes away, I need our team to continue her legacy by donating to the best researchers. You have to make decisions for her when I cannot."

It was at that moment I was reminded that our team was centered on the care of the entire family, and we were just as much a part of the team as they were a part of our family. They were there to nurture us, guide us, have honest conversations, and hold us up when we couldn't do it ourselves. I truly believe that due to the transparency and honesty that started at the beginning of our journey, we built a strong partnership. I knew I could trust them to make moral and ethical decisions for us should we not be able to do so. Our team knew us, we knew them; there was mutual trust, a bond. They were an extension of our family.

Our child went into inpatient hospice at the end of the summer and spent roughly two and a half weeks in the hospital before passing. Between the entire team and us, every need we had was met. The love, care, support, and concern that our team brought us allows us to reflect on our decisions and have no regrets. No regrets in treatment, quality of life, end-of-life planning, or postmortem tissue donations.

Transparency and honest communication build strong relationships among collaborative groups consisting of medical professionals and families. These actions through our collaborative partnership prove to be one of the most exceptional pieces to any healthcare journey that allows all parties to benefit when it is executed properly.