

A FAMILY'S PERSPECTIVE

Pediatric Palliative Care Stories



The National Institute of Nursing Research
extends its sincere gratitude to all of the
families who volunteered their personal stories
for this collection and the overall
Palliative Care: Conversations Matter[®]
campaign. It is our hope that sharing these
experiences will help others understand and seek
palliative care for their children and families.

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LEVI

My son, Levi, was born with severe brain damage. After three weeks in the neonatal intensive care unit, the doctor encouraged us to care for Levi at home with the support of a palliative care team. My husband and I were excited to leave the hospital, but frightened to care for our first child who also had medical complexities.

When we got home, our nurse and social worker were waiting. They stayed for a long time, helping us navigate those first fragile moments and building our confidence. Daily the nurse returned to help with questions and fears. He taught me to observe, care for, and communicate with Levi. He also helped me understand that I am my son's expert and advocate.

Our team used thoughtful questions to help us identify our values and make decisions about care for Levi, both daily and in an emergency. We worked through must-do and must-avoid lists. Our team also helped us understand the connection between the body, mind, and spirit.

When he was six months old, Levi caught pneumonia. Our team helped us with the details of how to care for him in a way that supported our care plan. Thanks to our team, we avoided hospitalization during a difficult two months.

Levi received home-based palliative care for four years as we gradually became more confident in caring for him. We spoke to a chaplain about our faith and the hard realities of parenting Levi. We engaged a respite volunteer who learned

how to care for Levi. We welcomed music therapy as a way to increase his comfort and joy, and to address issues like anxiety, pain, and sibling play.

What does palliative care mean to us? A team of people who know Levi – his history, care plan, challenges, and what may lie ahead. It means people who know me – my personality, preferences, and fears. It means a team we can call upon anytime. It means customized care with creative approaches that consider our values, culture, structure, and faith.

Palliative care also means fewer hospitalizations, which are expensive, exhausting, and risky. Levi has only been hospitalized three times in his five and a half years. Less hospitalization is one of many ways our team supports emotional and financial "savings" in our lives.

Levi was not expected to live beyond a few days let alone long enough to form a relationship with his younger brother. I can honestly say, without the partnership of Levi's team, he would not be alive today and enjoying such a high quality of life. We believe palliative care should be the standard of care for all families.

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AVERY

When I learned that my son, Avery, had a “life-limiting” illness, I felt that I had again failed as a mother. Why? I had previously lost three babies before they even had a chance on this earth, and I was now hearing that the life growing inside me was “more than likely never going to make it.” If he did, the prognosis was very grim. Avery was diagnosed with two very rare brain conditions, schizencephaly and Walker-Warburg syndrome.

Many people think I was given Avery because I am such a “strong, brave, knowledgeable” mother. The truth is that I am the one who was given the gift of a child like Avery. In turn, our family discovered the gift of a team of people who have supported us throughout our time with Avery.

During one of our many hospital stays, I was introduced to the “Butterfly Program.” Things like palliative care were discussed. Not wanting to feel as though I was “giving up,” I didn’t pursue this option for Avery. Several months later, I was again offered this service and it was the best decision I have made – for my son and my family as a whole.

From the initial phone call through today, the program has been a huge resource and comfort to our family. It has brought the most caring, compassionate people into our journey. Our team includes music and art therapists, a social worker, nurses, doctors, and a chaplain. His nurse, Kat, is an extraordinary woman who has always put Avery’s comfort and our wants and

needs first. She collaborated with me to give him what we wanted for him – a quality of life, not just a harsh existence. His chaplain, Paul, has prayed and sung with us, and enjoyed simple moments with us, as has the whole team. I truly cannot put into words what our social worker, Suzanne, has given our family. She has walked us through the hardest choices a parent would have to make – funeral plans for a child that you still hold in your arms. Suzanne was by our side helping us pick a spot for my son, something I thought unimaginable. Yet, because of Avery’s team, I have peace in my heart and mind that I am doing what we feel is right for our son.

There is never a moment that I do not have these amazing people there to help, to cry, to laugh, and to support his life, his journey, our journey. To say that this care is a great resource would be a huge understatement. Our team has been a gift of comfort, love, and sometimes the push that we needed to embrace Avery.

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JAKE

My son, Jake, is a beautiful 19-year-old, who suffers from mitochondrial disease and Dravet syndrome. These life-limiting, progressive diseases have no cure. Jake is developmentally delayed, has significant medical needs, and has hundreds of seizures per year. He lives at home with his family, and despite obvious challenges, Jake is generally a happy and loving child who enjoys a good quality of life.

Parenting a child with complex medical needs is, at best, stressful and challenging. It is often exhausting, frightening, isolating, and overwhelming. Those emotions can be mixed with feelings of great joy and gratitude. Sadly, a serious diagnosis often means a life-limiting prognosis, and an ever-present worry about end of life. Parenting such a child long term can be especially challenging. On one hand, you have the gift of time with your child, and yet, there can be years of uncertainty, grief, and full time caregiving and care management.

What can make a world of difference to such patients, parents, and families? A network of resources and care providers who can help to ensure support at each stage of the journey. Our family was lucky enough to have an insightful and compassionate physician who referred us to a statewide pediatric palliative care network in our home state of Massachusetts. Unfamiliar with palliative care, I mistakenly associated it with the end of my child's life

and avoided it. It took a few gentle follow-up conversations with our physician before I was ready to welcome palliative care and to explore what it could offer.

Here's what palliative care has meant to us. It has provided Jake with years of comfort care, including music, massage, and pet therapy, helping him to feel happy and relaxed. It has provided us with a medical team who knows our family, understands our goals, sees the big picture, and helps us think through difficult decisions. It has allowed us, at our pace and without judgment, to discuss end-of-life planning. Whether it is a therapist, nurse, social worker, or chaplain, we have benefited from a team of caring and resourceful providers who have our family's best interests in mind.

Seven years later, palliative care continues to be an essential part of Jake's care. It provides comfort, helps us maintain a good quality of life for him at home, and makes sure our family is supported.

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MOLLY

“What do you want for Molly’s life?” As I sat in the children’s hospital, that question stopped me in my tracks. It led me to consider all of the hopes and dreams of my then seven-year-old daughter, to cherish each moment, and to think about making the most of her life. Just a year and a half earlier we learned she had severe pulmonary hypertension.

Molly faced many obstacles, including cardiac arrest, extracorporeal membrane oxygenation (ECMO), being placed on an artificial lung, and a serious brain injury. It was hard to believe that Molly would not survive. Even after meeting with the palliative care team, where we discussed the reality of Molly’s future, I never gave up hope! When palliative care was mentioned, my mind raced to hospice. I had no idea that the main goal of palliative care is assuring quality of life with a focus on living. The team empowered our family to live as fully and normally as possible, doing things like painting pottery and eating ice cream cones way past bedtime. Meeting with a physician, a nurse, and a social worker provided support to our whole family in many ways. It allowed us to share thoughts and fears, to get answers to questions we didn’t know we had. It also helped us support our other two children through the loss of their sister.

The palliative care team was there for us every step of the way. They assured us that they would do everything they could to assist our family. Members of the team were present at the end of Molly’s life and made sure that she was comfortable. They lifted us up after her passing and stood with us as we learned to pick up the pieces. They were an invaluable part of our health care team, and for that, we are eternally grateful.

We were so profoundly affected by our team that we formed a foundation, in Molly’s memory, to educate others about the benefits of palliative care. It is our hope that families of children living with chronic health conditions will be open to working with a palliative care team. We hope that they not fear it, but embrace it, as they figure out how to live to the fullest despite obstacles along the way.

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