The Family Voice

The Most Difficult Decision We Ever Had to Make

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ABSTRACT

The author describes her family’s experiences with hospice at home for their young son.

Our journey with Jacob in many ways felt like a lifetime and like just a few quick moments simultaneously. Our son was diagnosed with a rare genetic mutation that caused countless hurdles. During his life, he acquired a gastrostomy tube, a wheelchair, and eventually a tracheostomy.

Even before his diagnosis at age six, we knew his life could be short, and we did our best to give him a life full of meaningful and exciting experiences. At a monster truck event, shortly before being diagnosed, he went into shock due to his inability to regulate his body temperature; he was resuscitated after becoming hypothermic. A similar event happened a few months later, at which point the hospitalitist in the pediatric intensive care unit sat down with me. Her words were kind and we knew the day would come; we were at the crossroads of having to face that we had run out of options and his body was tired. Our next chapter in Jacob’s journey was transitioning to hospice through the Children’s Palliative and Hospice program.

The choice to begin hospice was a very difficult one. Thankfully, the palliative care physician and the team who cared for our son were constantly reminding us of the love and care that lead to decisions like hospice, and that it was not failing in any way. At the beginning of our hospice journey, I had a difficult time letting go of solving every “medical mystery.”

After a very complex and mysterious life followed by a rare diagnosis, it was difficult to not constantly look for the answer to every ailment and illness that affected our son. We had endlessly advocated for him and it felt wrong to not do so. Yet our primary hospice nurse reminded us time and time again that hospice is not about solving mysteries, it is about comfort and quality. She gently reminded me many times when I would ruminate about figuring out what was causing trouble that day, until I was able to take it to heart. It helped us so much.

Shortly after beginning hospice, we wanted to attend a family holiday party about two hours from our home. In the past we would have most likely not attended, telling ourselves it was too risky, too scary; but they encouraged us to get him there. Our hospice team helped us problem solve and prepare what was needed so we could make the trip with him.

He slept much of the day, but he opened his eyes to see Santa and he got to see cousins, aunts, uncles, and extended family. We didn’t know it then, but it

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would be the last time he would see many of them, and the encouragement to go was a perfectly timed gift. Our amazing hospice team also helped us to prepare for an epic roller skating seventh birthday party for him; another event where he saw many people who loved him and was able to find joy in the day.

We continued to make plans, no longer having to worry about burning all of his energy up for medical appointments. The appointments were done. The last one was his initial meeting with his palliative care doctor. After that visit, we were able to do televisits with her in the comfort of his bedroom and with our hospice nurse present. These visits were amazing. The convenience of not having to physically go anywhere was a blessing I can't even put into words. We were able to focus our energy toward joy. Early on, I had concerns the tele-visits would not be thorough enough, but having someone physically present along with the conversation made each appointment feel complete. So much of our hospice journey was in what we discussed versus the physical aspects of medicine.

Eventually, days came when he was very uncomfortable and we were almost constantly on call with his team. Nurses came out when we needed them; they guided us on keeping him comfortable with medications and other measures. They never failed to remind us that this was about quality and comfort. A few short months after the birthday party, the day came that we knew it was time to let him go. He was in a lot of pain, he was tired; it was the moment they prepared us for.

We decided, along with his care team, to help him be comfortable and remove the machines supporting his life. When we told his palliative care physician that we were ready, she quickly decided she would come to be with us to assure his comfort and help guide the hospice and homecare nurse. They held our hands and prayed with us when we prayed over our beautiful son; it just felt so perfect and right.

After he passed, we were able to just be with him and grieve. His nurse took care of every detail and guided us as we tried to process this unimaginable situation; we had support, care, and guidance right up until his small, seven-year-old body was rolled down the ramp outside our front door for the last time. Even after he was gone, they continued to care for us for months. Child-life visited our daughter and helped us try to understand her grief. A chaplain visited and spent an afternoon with me, talking about the little boy I missed and seeing his bedroom.

The care and support our son needed increased until his last day. We could not have done that last leg of the race without his hospice team. They were there supporting us through every step of the simultaneously heartbreaking and beautiful journey that is hospice.