

Inside Look

My Experience with Palliative Care

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When a pediatric nurse practitioner friend of mine suggested we investigate Palliative Care for our Molly, I was a bit confused and more than a little defensive quite honestly. Molly had a life long history of bowel issues. She recently had a volvulus (twisted bowel), and had nearly died. After weeks in the ICU and many complications, she was home and seemed to be ever so slowly recovering from this horrible experience. It is an understatement to say this was a really challenging period. She had so many new care giving needs. We felt completely overwhelmed, but why would we need Palliative Care? Palliative care is hospice care, right? Molly wasn't dying. We had hope for her future. An inner voice told me to find out more. We needed help. At times I felt like we were drowning in her ever-increasing medical needs.

My friend told me that Palliative Care was becoming part of the standard of care for medically complex kids, and was not just for those with a terminal diagnosis. I still felt like we weren't candidates for this service, but we were pretty desperate at this point to improve Molly's quality of life. Just asking her surgeon for the referral felt really uncomfortable. I listened to my gut. Why not see what they have to offer?

Once we met the Palliative Care Team at Boston Children's, we learned that they followed medically complex kids for decades sometimes. We told the team about Molly and our family, her medical journey thus far, and our concerns for her future. We felt an enormous sense of relief after meeting with the team for just an hour or so. It felt hopeful, not like we were giving up on our daughter. We finally had found partners to help us through the medical gauntlet.

My heart sank a bit as I realized how much Molly could have benefitted from Palliative Care so much earlier. A team to manage her pain and anxiety? Help us communicate our wishes for Molly with specialists? Improve coordination of her care? Help us find the language needed to articulate what was most important to us for Molly's quality of life? How had we missed out on this all these years? Sadly, in Molly's case, our experience with Palliative Care would be very short, but also provided us with the tools we would sorely need very shortly.

In our case, Molly would need the hospice services that are also a part of Palliative Care shortly. We didn't know when we met with the Palliative Care Team that Molly's small



bowel was now failing. We were back at Boston Children's in just a few weeks after she experienced yet another obstruction. We were faced with the hardest decisions of our life.

It's difficult to find the words to explain what having this team of caring, compassionate, understanding, and talented professionals by our side meant to us in our time of much desperation and angst. Their collective experience and wisdom helped us in so many ways. The team made multiple visits to Molly's bedside to discuss options and concerns, and to hold our hands, acknowledging gravity of the situation we were facing.

After Molly's small bowel ceased to function yet again, before even implementing the procedures we had chosen to try and help her, our heartbreaking choice became clear. The Palliative Care Team helped us articulate our thoughts to her other doctors. We transitioned Molly to comfort measures only. Palliative Care was heavily involved in setting this up, controlling her pain and providing emotional support to our family. Molly died peacefully six days later.

We miss our girl so much, but we are at peace with our choice to cease further treatment for Molly's long history of intractable bowel issues. By sharing our story, we hope to educate CdLS families about the benefits of Palliative Care for children and adults with complex medical needs. Our only regret is that we didn't access these services sooner.

