



Impact of Support for the Harriet Lane Compassionate Care Program

Palliative Care in Adolescence Medicine

Sam is a young adult who has been dealing with her chronic illness for a number of years. She has managed to go to college, travel and have a lot of the experiences many her age have. However, as her illness has gotten more serious, her mother has needed to move in with her, she has needed to drop a number of her grad school classes. She is now contemplating a serious surgery. Our palliative care team had the opportunity to get to know Sam and her parents over the course of a series of difficult procedures and surgeries. Sam is very independent, hilarious and smart, but these aspects of her personality can easily be overshadowed by her anxiety. The palliative care team worked really hard to help Sam individually, as well as Sam and her mom together, to access effective coping strategies. They helped Sam work through different medication options, and they were able to take a closer look at every procedure option for Sam, to weigh the costs and benefits. Sam has made it through difficult procedures which has helped her gain confidence in taking the steps to work against her illness. When you hear the words “it’s going to be okay” – it only matters if you truly believe it will. Our palliative care team helped Sam believe that it will be okay. For Sam, and for this family, continuing to pursue disease directed treatment is really important. This is not the case for every family. The beauty of palliative care, is that we follow the family’s lead. We know that this is important to Sam, and because we know this, this is where we start.

It is the role of our pediatric palliative care team to come up with ways to help patients like Sam cope, to give them a voice in their own care, and to help parents balance their role as mother, father and cheer leader. In Sam’s case as in many others, our team – from the palliative care director all the way down to the support specialist and chaplain, works hard day in and day out to help this family as they work through the challenging hospital landscape, meeting with specialists across a number of different disciplines. “I have found that often this is a role that we can play in palliative care, but not one I expected to play,” says Cora Welsh, MA, CCLS, a senior child life staff member who specializes in pediatric palliative care and bereavement support. Cora continues, “We have the great privilege of learning so much about the families we work with, and getting to know them really well. We learn the fun things and the hard things. We are also in great position to teach patients and families about how they become advocates themselves, to communicate with other team members and enhance the relationships they have with their own providers.”

Sadly, shortly after this story was shared, Samantha passed away. Just as the palliative care team helps patients and their families, patients like Sam help our team too, and they live on through the work the team does. Sam’s story reminds us that deep down everyone has the ability to cope. It’s the team’s role to help patients and families find the thing that works best for them, to give them the comfort when it’s needed and space when it isn’t.



Impact of Support for the Harriet Lane Compassionate Care Program

Palliative Care in Neonatology

A family arrives to the Johns Hopkins Children's Center late in their pregnancy. This was a first child for the father, a second baby for the mom. Her first baby died, and she carried many painful scars from that first sad loss. Both parents knew their sweet baby girl, soon to be named Finley, had serious health concerns and it was unlikely she would live a long life after birth. Nevertheless, they hoped they would get to hold her, kiss her, sing to her, and snuggle her. These loving parents asked to meet with our team of pediatric palliative care specialists in an effort to plan for the hours, days or weeks of their daughter's life. As the pregnancy drew to an end, the parent's anxiety and sadness began to increase. Managed with the help of our palliative care team, the parents learned the best ways to interact with the other members of their medical team and how to maintain good communication lines with them.

Well-trained palliative care specialists were able to figure out where some of the family's fears were coming from related to the anticipated delivery. While pregnant, mom and dad knew the baby was always safe. After delivery, the panic of the unknown would soon set in. The palliative care team took the "what can you do with your baby in the time you have" approach. They helped them think about trips to the Inner Harbor, going out to eat for the first time, attending church and of course what Finley's first trip to the zoo would be like. They even helped them imagine her first Christmas. Through these emotional and lengthy conversations, allowed by support for the palliative care team, this family was given room to grieve in advance and to create more days of "in utero" memories before scheduling the delivery appointment. Finley lived only for a few days, but those days were filled with cuddling, opportunities to nurse, take photographs, lots of kisses from daddy, stories from Uncle Joe, a Baptism from Rev. Uncle Jim, a dress made by Aunt Sarah, drawings from lots of cousins and so much love. Those few beautiful days her of life were about just that, life. Above all, support for our palliative care teams allows for more families to have moments like this at the Johns Hopkins Children's Center. Turning sadness into healing and grief into memory.