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Lessons from a child

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Eight and a half years old. Forty-nine admissions to hospital, 35 emergency department visits and 152 outpatient hospital visits, for a total of 822 days in hospital. At least 17 broken central venous catheters (CVCs) that required repair or replacement, 12 new CVCs and 6 peripherally inserted central catheters. Nineteen episodes of septicemia and seven of fungemia, all of which were life threatening. This was my friend Sheyanne.

I first met Sheyanne when she was one month old. She was born in a community hospital, into a rural and strongly faith-based Mennonite family. Shortly after birth, it was noted she had problems and she was transferred to Children's Hospital in London, where choanal atresia and imperforate anus were diagnosed. These were repaired, but every time feeds were started, she developed explosive diarrhea.

As a hospital-based pediatrician who cared for many of the inpatient children with serious bowel problems, I assumed her care. For the next eight-plus years, I was her primary physician caregiver. At the age of three months, she was given a diagnosis of congenital sodium secretory diarrhea and was committed to a lifetime of total parenteral nutrition (TPN) via CVCs. Her dietitian and I, along with the nursing staff, became her treatment team. Having cared for pediatric liver and bowel transplant patients for more than 20 years, I was used to talking with patients and their families about life, death and treatment options, and I had been to many funerals for the patients who either had not received the organs they needed or who had developed complications following transplantation. Those patients were unwell, but transplantation gave them a chance to live. Sheyanne didn't have the option of transplantation. She was a patient unlike any other.



Along her journey, Sheyanne taught her medical and family caregivers a great deal about TPN and medicine, about the fixing and replacing of venous catheters in a very young and active child, and about the various presentations of serious infection. More importantly, she taught many of us a lot about zest for life. For the first 13 months of her life, she lived in hospital; from the very beginning, she was a strong-willed child, exhibiting a toughness that I believe kept her alive on many occasions.

Her dietitian and I worked with Sheyanne's mother and the family's support network to get her home with TPN. Although it was an enormous challenge for the family, with three other lively children, they were committed to her care and

became proficient at feeding her through TPN. Over the next several years, I grew accustomed to receiving pages from Sheyanne's mother, saying that her daughter's line was damaged or an infection was brewing. I would arrange for a bed for Sheyanne's next admission and her parents would make the two-hour drive to Children's Hospital.

Despite the numerous hospital visits, admissions and episodes of life-threatening infections, Sheyanne remained full of spunk and laughter. I used to be Dr. Paul, but by the time she was six years old, I was just *Paul*. A bright, curious, exploring child, she eventually figured out how to page me herself, calling me from inside the hospital when she was admitted. She came to believe that time with Dr. Paul meant she

would start to feel re-energized, as once her infections were treated, she would bounce back to her delightful self.

We, her medical caregivers, could not help but grow to care deeply for Sheyanne and also to expect that we would be treating her for the rest of our careers. Her stays in hospital were often prolonged but, provided she was not bedridden with sepsis, she would be out touring the corridors of her hospital floor, eager to jump out and surprise us or show us her crafts. Other hospital staff embraced Sheyanne's outgoing personality; one day this past year, Child Life Specialists took her to Customer Support, where she received an ID badge as a helper. She was so proud of it, inviting the health care team members to notice her working as she helped push some of the other children around the halls in their strollers or wheelchairs. The nurses delighted in her and there was always a hint of sadness whenever she was finally able to go home to be with her family.

As at other children's hospitals, "Make a Wish" experiences are made available to our very ill patients. Just three weeks before she died, Sheyanne went to Toronto for a Make a Wish trip with her sisters and mom — and they did about as much as you could do in a week in the big city. Sheyanne was excited to capture these memories on her new iPad — a gift she had received

shortly before the trip — and with glee shared all the pictures with the staff after she was admitted to hospital.

This would be Sheyanne's last hospital visit — the last of many. Earlier in her life, I had talked with the family about intestinal transplantation and we all agreed this would be an unreasonable course for Sheyanne and her family — after all, when Sheyanne was not at "death's door," she was a happy and vivacious child. So we continued to treat her recurrent infections, but after a while, the cost of treating these infections — on Sheyanne, on her parents, and on the family as a whole — became enormous. Sheyanne was still vibrant and mostly happy, but her suffering had outpaced her healing.

Eventually, no more alternative sites for new CVCs were available, and Sheyanne would have faced death by starvation and/or dehydration. Confronted with this choice, we once again introduced the option of not treating the infections. By this point, Sheyanne's parents saw that her quality of life was deteriorating and, knowing what she would have to deal with, in consultation with me and others on her team, they decided that it was time to let God, rather than science, decide her fate.

Sheyanne's journey has deepened my understanding about quality of life. Although I have walked the path with

patients and their families of coming to the decision to withhold treatment for a terminally ill patient, this ending was different. The life and optimism Sheyanne exuded when she was well made this especially difficult for all of us involved in her care. But by her last hospital admission, even those who did not initially agree with the decision had come to accept that a tipping point had finally been reached: it was time to compassionately let her go.

As we partnered with Sheyanne and her family during this journey — we provided palliative care and kept her comfortable with medication during her last infection, which we did not treat — it gave me a deepened appreciation for the challenges involved in withholding medical intervention when it will not enhance quality of life. And I will continue to treasure the many lessons Sheyanne taught me and my colleagues about finding balance between the benefits and intrusiveness of medical care, quality of life, living in the moment, caring deeply — and letting go.

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This article has been peer reviewed.

This is a true story. The author has received consent for this story to be told.