# Sylvie's Story

"When our oncologist broached the idea of palliative care, she pointed out that it was not an admission of defeat against Sylvie's disease. The care would step in and help as necessary, and step out when no longer needed. Even so, at the time we thought that it was the beginning of the end. Our perspective has changed since then. We take nothing for granted; we know that we have a long road ahead of us, and that Sylvie will always have her tumour. But we have seen her capacity for improvement. We are hopeful. "

On October 10th, 2013, my husband and I suffered a devastating blow: our beautiful 8-month-old baby girl, Sylvie, was diagnosed with a brain tumour. It happened while she was on her third hospital admission for failure to thrive. For the previous several months she had been struggling to gain weight despite all our best efforts, including feeding her through a feeding tube. By the time she was diagnosed, we were already worn down from the enormous stress of the situation. But even though it was terrifying to hear 'brain tumour', once we regrouped and learned more, we felt something akin to relief for at least knowing what was causing her malnutrition. The prognosis was relatively positive. We were told that while her tumour was inoperable, it should respond to chemotherapy and she should be able to live with it rather than die from it. When she was diagnosed, Sylvie was doing everything one would expect an 8-month-old to do. She was hitting her developmental milestones and charming everyone around her with her smiles and sweet personality. Unfortunately, we had to watch all of that slip away as the tumour started to take over in a way no one anticipated. Even before chemotherapy got underway, Sylvie became sleepier and sleepier, until she slept most of the day and night. She also became extremely nauseous. She spent most of her time in her bouncy chair, being fed through a tube, sleeping and vomiting. She lost her sight, as the tumour grew and caused her optic nerves to atrophy. She no longer smiled, interacted, or made any sound. She clearly felt horrible and generally seemed 'out of it'. Her older brother, Cian, who had always been so besotted with her, started to ignore the ghostly presence that she had become. A baby who couldn't respond and smile was no worthwhile playmate. At the end of December, after Sylvie had been in chemo for about 10 weeks, she was diagnosed with hydrocephalus. She immediately underwent surgery to be fitted with a shunt to drain the buildup of cerebrospinal fluid. She also had her first MRI since her diagnosis, which confirmed that the tumour had grown significantly. It explained her sharp decline. It was at this point that palliative care was discussed with us by Sylvie's doctors. I had always thought 'palliative care' was basically pain relief for dying people, but the doctors explained that the purpose of palliative medicine was symptom management. On a day-to-day basis, Sylvie's worst symptom was her vomiting, and while she was already taking some different medications for it, we were open to new perspectives. We met with the palliative care team in Crumlin soon thereafter. We immediately felt their sympathy, and were so grateful to have experts look at all of Sylvie's symptoms and try to come up with novel solutions. Some new medication was prescribed, which had a perceptible benefit. What we hadn't expected was the offer of help in the form of home support for our family. As Sylvie's health declined, we had become housebound. Sylvie wasn't fit to take out of the house either during her tube feeds or between, as any movement could make her vomit. Through the palliative care team, we were referred to LauraLynn House, who could offer some home nursing care for Sylvie to allow me to get out of the house to run errands or spend time with Cian. Additionally, we were approved for a home care package by the HSE. In total I am able to take a couple hours out of the house every weekday. The offer of home support was a huge relief for us. While my husband's family is from Dublin, they are not in a position to offer the daily, specialised care that Sylvie requires. Also, I am from America, and while my own mother had come for several months when Sylvie was diagnosed, she needed to return home. The home care nurses could not have come at a better time. Sylvie is looked after by four different nurses, who are all kind, caring, and experienced. They are welcome presences in our home. In the midst of getting our home care package set up, the unexpected happened: Sylvie started to show signs of improvement. At first we thought it was just the benefit of the shunt relieving pressure in her brain, but her next MRI confirmed that there was a small bit of tumour shrinkage. Sylvie has continued to improve in ways that we had not thought possible. She isn’t as sleepy or nauseous. She is getting stronger and has started to develop physically, as well as in her communication and interactions. While she is well behind her peers developmentally, she now smiles, coos, laughs, plays, and loves her brother, parents, and cuddles. She has also started to gain weight for the first time since her failure to thrive started. She is feeling better and it shows. 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