

# **we planned our future, but then the present came crashing down**

*Celestine Caplan*

How do you break the news to a nine-year-old that her little brother is dying?

I am Victor's sister.

I grew up in the only house he ever got to live in.

On March 1st, 2007, we moved into a house in Ravenna.

Four days later, a newborn Victor came home from the hospital. He slept in my parents' room, in what used to be my cradle. After nine months, he finally started sleeping through the night. This is when he moved in with me.

We shared that bedroom for a while, him in his crib and me in my bed with the bumper on. We listened to audio tapes during quiet time. It wasn't a big room, but there was enough space for both beds. At night, once I was able to read a bit, I was in charge of story time with him while we lay in my bed together and sometimes in his crib, too.

Eventually, by the time I was five, my grandfather built two bedrooms in the basement. So I moved into my brand new room as I started Kindergarten.

When we were little Victor and I especially loved playing outside together. We captured any critter we could find, including slugs, ants, or ladybugs, and we observed them for hours at a time. Once, we even made a small house for a caterpillar, complete with rooms!

We also painted outside. Painting the fence was really exciting for us. We had tempera paint and our parents let us design the art that went on any structure outside, pretty much anything we wanted. It almost felt like we were breaking a big rule.

We loved biking in the alley. Victor actually learned to ride a bike without training wheels before I did, as he had balance superior to that of any other kid his age when he was two.

Victor was obsessed with wheels. He looked at the vehicles outside our window and stared at the spinning tires as they rushed past our house. Automobiles with sirens were especially entertaining to him as he ran to the window and observed intently as they screamed by. He then reported back to the kitchen proclaiming, 'red ambulance!', or 'ladder truck!'

Victor and I often planned what our future life would be. One time, my mom mentioned that we wouldn't want to live with her when we were older, and, after my initial surprise that that was not only an option but inevitable, I decided I would live with Victor. He was ecstatic that I had decided to include him, and we concluded that he was going to be a pilot and I would be his copilot. We had everything planned out, but then, one fateful Father's Day, my mom whisked him to the ER and I never again saw the same little brother that had been running around outside, laughing gleefully in the sprinklers the day before.

Of course, I saw him, but it was different because when he came home from the hospital two weeks after his terminal brainstem glioma diagnosis, in 2013, Victor was unable to eat, speak, pee, or walk. He had a feeding pump and a nasal-gastric tube, as well as a catheter. My parents brought an extra bed into what was then only his room and took turns spending the night there, in case his feeding pump had a problem, he needed anything, or he was uncomfortable. They didn't exactly get any rest as he was taking dexamethasone then and barely nodded off for 10 minutes at a time. In those days I crashed in my parents' bed.

Once he started sleeping better, about five months later, I moved back into our old bedroom with him and slept there every single night for the rest of his life. We went from his birth to his death in that room, minus some time in the middle. Incapacitated as he was in 2013 and '14, he was as helpless as his baby self from when we first shared that space. Watching him transform from the most annoying, amazing, loud, energetic, funny, active boy I knew to a feeble, diminished cancer victim irritated me to no end. I was powerless to stop the tumor and everything it brought and took away from him, and this not only angered me for his loss, but for mine as well. How do you go from having a playmate all your life to suddenly being alone?

Every night after his discharge from Seattle Children's, Victor asked me the same thing, "can I sleep with you?" and every night, when I said yes, he laughed. The sound of his laughter was quite rewarding to me, and nightly I strived to hear it.

One time I remember well was on my birthday. He had me wheel him around the house for a kind of scavenger hunt. My mom had hidden sticky notes in various places, and when we got close to one, he made an exclamative noise and I looked in all the obviously wrong places to make him happy before finally "finding" it. This went on to lead me to a note I still have, on which is a face that has his eyes closed and Zs streaming away from his mouth.

This was about four months before his death. The whole time he was alive he was joking and laughing at our attempted distractions from his current critical state of being. I happened to have this particular task. I was his self-appointed protector in Disneyland, Victor's Make-A-Wish trip. I was my brother's keeper. I warded off the pesky questions we received from foolish families about Victor's NG tube and adapted stroller that sprouted tears in my mother's eyes despite our "I'M A WISH KID/PARENT/SIBLING. ASK ME ABOUT IT!" pins.

One of the many things I learned along this godforsaken journey is that when you're part of a Wish family, the tooth fairy is generous. I got ten dollars for a tooth with an enormous cavity. Maybe to take my mind off of THIS.

This hell I wouldn't wish upon anyone.

This hell many of our family friends pretended to know to act sympathetic.

This hell where you don't know why your neighbor is waking you up at six in the morning on May 14, 2014 until you get to the ER and your mom tells you your brother is dead.

This reality not sinking in until a party three years later when you are the only one without a sibling to give a piggyback ride to.

So I can't say that I know the best way to break the news.

There is no good way to tell a nine-year-old her brother is dying.

No matter how you slice it, nothing you can do will soften the blow. Life will never be the same again.

Cancer sucks.