Eyes Closed and Mouth Ajar

I feel like a fish, flopping about in a murky pond. The sun is beating down on my face; I try to escape the heat by diving underwater. Courtney splashes me as she submerges under. A shriek comes from a girl getting dunked by her brother, splashes sound from all around, yet through it all, I can hear my brother yelling my name.

“Hope!” he shouts. “Courtney! Come on,” he continues. His voice is deep, his brows are furrowed together. I can see his hands twitch from the distance, and by the way he takes short puffs from his Marlboro, I know he's stressed.

I began to paddle towards the shallow end, I clamber up the mossy steps and stumble towards my towel. I look over to Courtney, and she’s still in the water. Ignoring her, I struggle to keep up with my brother. He’s moving so fast!

We’re heading back to my camper. The soft grass soon ends, and I’m left walking barefoot on stones. They sting the soles of my feet like blazing charcoal. I concentrate on avoiding the big stones, and finally, a patch of green. I gladly hop onto the comforting grass, and now I can figure out why I was called back to the camper.

I look up see a red and white bus with flashing lights on top. My heart skips a beat, and then decides to plunge into the pits of my stomach.

I stop walking as I reach the edge of our campsite, and just watch the havoc crashing all around me.

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For as long as I can remember, my sister has always been different. And for a long time, I never wondered what was wrong with her. Because as different as my sister was, she’s still normal to me.
Growing up with a sibling with Rett syndrome (a disorder of the nervous system) isn’t always the most convenient. Instead of watching a new SpongeBob that’s on TV, you get to watch Barney’s Adventure Bus for the hundredth time this month. When you’re walking around the store, and your sister’s legs begin to give out, you get to be the one to hold her up as she regains control of her legs.

These are only two of thousands of inconveniences my sister, Katelyn, brought to the table with her disability. And while she was alive, those thousand inconveniences were all I noticed. I didn’t notice the million great things my sister taught me.

Katelyn couldn’t speak, but I learned that you don’t need to use words to communicate. Everyone knew that when Katie swung her arms around and walked with a bounce in her step that she started her day off on a good note, that note probably being a bowl of fresh Cheerios and an episode of Barney. She has feelings just like anyone else does. Just because she couldn’t speak or write our language, she wasn’t any less smart or special than anyone else.

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My feet are cemented in the ground, and my body has turned to stone. I can’t move, all I can do I watch.

Katelyn’s lifeless body is sprawled out on the patio floor. A paramedic is kneeled over her, filling her lungs with air in hope of regaining her lost life. I tear my eyes from the patio, and look in the front lawn where my mom sits.

Her frizzy, brown hair is clipped back. She’s wearing shorts and a tank top. With red cheeks and teary eyes, she is quietly sobbing.

It’s too much. I sit back on the golf cart, facing away from all that’s going on.

Everything is a blur until my step-dad, Ken, returns back at the camper to take James and I to the hospital.

I climb up into our big van. A few minutes into the silence, Ken answers the unspoken question James and I were thinking.

“You know she’s gone, right?” he asks softly.
My throat is on fire, and my eyes are holding back tears. I gently nod my head, I don’t know if anyone noticed. I fixate my gaze on the passing trees, pushing aside the tears I don’t want seen.

And suddenly, I’m walking through the hospital doors, taking a right twice. My hand is on the cold metal handle of a white door. I turn the nob and push the door open, revealing a white room.

My sight is fixed on her again. Only this time the view is burned in my memory. I know I’ll never forget the image of my sister in that hospital room.

Her eyes are closed lightly, her mouth slightly ajar with a plastic tube emerging out. There is blood crusted around her mouth. Her frizzy, blonde hair spills out of the ponytail she fell asleep in and strands stick to her forehead.

I peel my eyes from her, to turn around and see my family watching me. A box of Kleenex has been emptied, I feel like I should be rowing a boat through the streams of tears being shed. All these tears, yet where’s mine?

My dad bursts through the door.

“How’d this happen?” He barks, his eyes are squinty and red. He says something else, but his voice is cracking so much I can’t make out any words.

I don’t want to watch this, I don’t want to be here. Was it just last night we were watching fireworks in the park?

My thoughts are interrupted by my aunt, coming up to me and resting her hand on my shoulder. She leans down and whispers into my ear, “Go say goodbye, Princess.”

She leads me up to my sister. All the eyes in the room are on me, but my eyes are on her. Her chapped, plump lips wrap around a plastic tube. The normal, clear saliva she drools has been turned into blood. Her cheeks are pale, her eyes are closed, mouth ajar. She looks so peaceful. I kind of want to nudge her awake like I do every morning.

I snap back to reality as my aunt softly urges me to speak. But I can’t. My eyes dwell with tears, my throat closes and catches on fire. I can’t move. The sadness has taken over me and I can’t deal with it.
I have to fight back the tears. I just need to say goodbye. It’s just one word. I can do this.

I swallow the lump in my throat, blink back the tears, and take a deep breath. With the little energy I have left, I seem to muster up just enough to speak an inaudible “Goodbye.”

I’ll explain it like my mom explained it to me. Girls with Rett syndrome sometimes don’t survive through puberty. Being the age of thirteen, my sister was just beginning to go through that stage. She died peacefully in her sleep that night, no explanation for it. I like to comfort myself in the fact she’s in a better place now, walking and talking with all our passed relatives. And that maybe I’ll see her again one day.