Telling Nick

Category: Stories
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Marianne Lonsdale

“What’s going to happen to Catie when she grows up?”

I was driving with my son, Nick, to the store when he asked this about his fifteen-year-old cousin, Catie. Nick, age eight, had just spent his spring break at Catie’s home. Blind, she was now losing her ability to talk, but she always recognized Nick’s voice. She adored having him by her side; whenever Nick walked into the room, her face lit up, and she raised her arms for hugs. She was the closest Nick was going to get to having a sibling.

“Will she get a job?” he piped up from the backseat. “Or will someone still have to take care of her?”

Small for his age, Nick was just about big enough to stop using a booster seat, but still young enough to be afraid that monsters in the closet were real.

I’d been wrestling with when to tell him more about Catie. Now, here came this question from out of the blue.

“Her mom and dad will always take care of her,” I said. My first instinct was to assure him that everything would be all right—that monsters weren’t real.

But Catie wouldn’t be all right ever again. Even when Nick was a toddler, he’d noticed that Catie couldn’t do everything he could. Over the next few years, he’d watched Batten disease destroy his cousin—blinding her, shutting down her brain, turning her muscles to mush. Now she traveled in a purple wheelchair. Her speech was garbled, but she somehow still belted out Celine Dion ballads, and her smiles were endless. We always felt joy from Catie.

Catie had been nine when she started losing her vision. By eleven, she was blind. She also had frequent seizures. Some were so slight they could be seen only on brain scans; others caused violent convulsions. Nick never got used to seeing the seizures.

At first, doctors puzzled over her symptoms. Years of testing and waiting for results passed. Catie would be thirteen before she was diagnosed with Batten disease, a genetic disorder caused by an enzyme deficiency in the brain cells. It’s so rare that her neurologist had never heard of it.

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The odds of two parents both carrying this rare recessive gene is small and self-limiting—only 500 children in the U.S. are estimated to have the disease. But if both parents are carriers, then there’s a one-in-four risk that their children will develop it.

I’d kept many details of the disease from Nick. I hadn’t told him that, over time, Catie would suffer mental impairment and worsening seizures, that she would become bedridden and barely able to communicate. I’d shielded him from this—and from the most brutal part of all.

“Honey, kids with Batten don’t live long lives,” I said. “They don’t usually make it past their teenage years.”

A guttural wail poured from Nick. He sobbed, his whole body rocking forward and back.

I pulled over, climbed into the back seat and pulled him to me. He slid his hand up my sleeve and rubbed my arm, leaned his head on my shoulder.

I winced, wondering if I should have just thrown the information at him like that.

“What’s happening with Catie is one of the worst things you’ll ever have to deal with,” I said. “Honey, I am so sorry.”

Our day wore on. I told my husband. I emailed Nick’s teacher, asking her to let me know if she saw any unusual behavior.

Nick said no more until a week later, when I was reading to him at bedtime. His hand closed the book I held. His blue-grey eyes were moist.

“I keep thinking about Catie. At school, at baseball practice, all the time,” he confessed.

“I think about her a lot too,” I said. “It hurts so bad.”

Nick nodded, his mouth trembling. His hand tugged at the elastic waist of his blue flannel pajamas. His teary eyes closed.

I missed Catie already, and I ached for Nick, who would lose his cousin and have to attend her funeral. Damn that disease.

Epilogue:

Caitlin Rose Allio died on Mother’s Day, May 13, 2012. She took her last breath in her mother’s arms. She was twenty-two, an elder of the Batten community. Nick, now a gangly fifteen-year-old, hung out with Catie that weekend. On the day Catie died, Nick said goodbye, kissed her and rubbed her shoulders. As always, she smiled.

I was so impressed with Nick’s compassion for Catie and her family, and his willingness to be present with them during Catie’s last days and at the memorial service. In the days after Catie’s death, he said to me, “Whatever they need, Mom, is what we need to do.”

Catie’s youngest sister, Annie, is thirteen. She too suffers from Batten disease. We all believe in monsters now.

About the author:

Marianne Lonsdale writes personal essays and short stories and is developing a novel. She is a founding member of the writers’ group Write On, Mamas! She also belongs to Left Coast Writers and is honored to be an alumnus of the Community of Writers at Squaw Valley. “My dual muses are my husband, Michael, and my son, Nicholas.”

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