

As read by Elizabeth Roach for
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I knew from the beginning that if and when the day came (and I both knew that it would, and knew that it wouldn't), I would tell this story. On winter weekends, from the time Owen and Leda were old enough, we'd drop them off at Catamount and enter them in the Ski-Wee program. Leda didn't love skiing, but Owen did, and continued through the years with a triumvirate of buddies who also spent weekends in the area, shifting from skis to snowboards according to the trend.

At first, Ed and I, not skiers ourselves, had spent mornings in the lodge with a book and a hot chocolate, but as we grew more confident in the kids' safety, we'd drive the 20 minutes back home to our country house, and spend the mornings there. Which is to say, we'd never really witnessed our boy coming down the slopes, or saw him ski until...

Our house is on a hill at the top of a long, steep driveway, with a degree of incline verging on the illegal. One morning, after a heavy snowfall, before the plow arrived, Owen asked if we'd like to watch him snowboard down it. We agreed with some trepidation. We took our places at the bottom of the hill, and Owen at the top. I imagined the herky-jerky procedure, the only one possible, down this steep, narrow trail, bordered by tall trees and deep ditches in which our car had been stuck innumerable times. What followed defied all expectations. Owen flowed down that makeshift slope in a single motion, a whispering trail unspooling behind him in a smooth series of perfect ess curves from beginning to end, the absolute picture of grace.

And that is how I imagined Owen would get through this ordeal— glide above it, rather than fight through it, and, at the end, walk away free, leaving it behind him. He did glide above it, in a sense, never complaining, or railing against his fate, never losing patience, and never, not once ever, asking for or receiving even the smallest service, without a please and thank you.

Because for the last several months video games, TV and even playing Catan online made him dizzy, he would just lie on the sofa in quiet contemplation, seemingly never experiencing, or at least never admitting to boredom. This was hard to comprehend, but Owen always did have a talent for inward focus, as anyone ever trying to gain his attention might know; this often required addressing him by name, waiting a polite interval, and then repeating his name once or twice, sometimes loudly.

He defied his increasing debilitation, getting around the apartment without assistance, his risk of falling growing ever more serious. After one 24 hour visit to the hospital, Owen was awarded an aluminum cane with white rubber stoppers. In the

small spaces of a New York apartment, the thing, aside from being ugly, was more hindrance than help. Ed hoped that something more whimsical might fit the bill, and presented him with a tall, knobby walking stick. This did the trick and Owen did, indeed, put it to immediate use. (Short video).

How harrowing would those hospital visits have been, the consults, the check-ups, the treatments, had we not faced them together, and had Leda not kept up her lively banter and stories, instilling a sense of normalcy and making us laugh. She held Owen tight within their unique sibling relationship, greeting him always with one or another of their singular and peculiar terms of endearment, and engaging him in talk of sports, Ed and me, and Harry Potter.

Towards the end, there was not much we could do for Owen. Leda helped him to episodes of Parks and Rec, and he was happy to accept an offer of water or chapstick.

Stacia, his girlfriend, concerned herself mightily with his physical environment. She made sure that his clothes were soft and cozy, would tuck a blanket over his legs, or arrange the pillows beneath his head just so, to such good effect that Owen bestowed upon her the well-earned title, Grand Master of Comfy.

What do you say about this Grand Master of Comfy who met a handsome young man with a serious medical condition, and instead of fleeing, leapt right in? Or rather, how do you ever stop talking about her?

We first got rumblings of Stacia's existence a little over a year ago, when Owen would pop downstairs from his small apartment just above ours, to borrow a couple of bowls, or a set of measuring spoons. I once spent an hour looking for my cheese grater. Rumblings grew louder one dark December afternoon, when Owen entered our kitchen bearing two plates of colorfully decorated Christmas cookies, saying, "Look what I made!"— We looked at him in surprise, then incredulity, to which he said, "Well, I decorated them," and finally "Well, I helped." Amongst them was a heart shaped cookie, tidily bordered in red, bearing a perfect pale blue S in the center. We still have it. That was our first clue to the identity of mystery woman. I was told I'd never guess her name.

Nor did I. For weeks afterward, I pestered the doormen for information about her, but all they would do is nod and say, "She's nice." At last, not long after New Year's, with a pride that our modest son could not keep from bubbling up, he announced that his girlfriend would be joining us for dinner the following night.

She became an immediate member of the dinner circle, then of the family, her family scooping Owen into theirs, their family becoming ours, including her friend Morgan.

All this happened without question or discussion, soundlessly, invisibly, in a process that I can only dub Stacianet.

Her pale beauty which we first encountered that evening, continues to reveal itself, layer after layer, to inner depths of staunch courage and personal responsibility. She transformed the worst year of Owen's life into an idyll that existed side by side with sorrow and terror; an idyll of golden and ever deepening intimacy, of laughter, trust, reliance and comfort. The life they packed into that one year was rare and rarefied, full of sweet, slow mornings and smoothies, game days with friends, long hours of Catan, home cooked, candlelit dinners in their little apartment, lovingly referred to as "The Nest," chocolates and ice cream desserts, always topped by Stacia with something to put it over the top, long walks with Stacia's family in the beautiful park at Kykuit, birdwatching and sunsets at Stacia Point, and Harry Potter Audible lulling them softly to sleep in the dark.

In those last days, it was Stacia, with the help of Sasha, who stayed into the wee hours at the ICU, reassuring and comforting, the three of them woken hourly when the nurses came in to check up. But you were all there too, visiting, or emailing, toting in oceans of food, sustaining our family and keeping the real Owen alive and well. And, while the doctors were amazed that he was capable of speech, he was actually at his most profoundly Owen, always thanking the nurses, and remaining his good old self to the end. Among the many heartbroken and prayerful emails that came to us at the hospital was one requesting that I let Owen know that the writer thought often of how brave and smart and cool Owen was. I dutifully relayed this information to Owen, to which he replied "I think about that quite often, myself."

Laurel