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Making Plans

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The blood drips down the transparent transfusion tube, through the needle, and into my sister's vein. It will mix with hers and keep her alive for one more month. Sometimes, when it's not a perfect match, it gives her a bad reaction, some swelling in her arm, or, worse, a fever that will last for days. She's lucky. Her blood type is O-positive, the most common and easily available. She rarely has to wait more than a few days past her deadline for a donor to show up with a match.

She's affected with Beta Thalassemia, also known as Mediterranean Anemia because it is so common in Mediterranean countries like ours, Italy. Her body does not produce hemoglobin, a condition that results in the premature destruction of red blood cells. Monthly blood transfusions are the only way to keep her alive.

My sister's incessant jabbering filters through my thoughts and brings me back to the present, to this hospital room, this metal chair next to her bed.

"And then I told her that I was really sick, and I might die. She teared up and gave me an A." My



sister laughs at her own cleverness, feeling no remorse for manipulating her instructor.

“Simona!” The nurses stop what they’re doing and mock-frown at her. “How could you?” They laugh anyway and tell her she should be a comedian. Simona, pleased with the attention, continues to crack jokes with anyone who’ll listen—the doctors, the other patients, the visitors. She has a wicked sense of humor like my father. She cracks jokes about hospital life, and about herself as much as other people, and the nurses double over with laughter and beg her to stop or they’ll pee in their pants.

This is her world. This is home. Medicines, hospitals, doctors, and procedures have been her steady diet since she was five, when she was diagnosed with this genetic illness. In Sardinia, the island of our birth, it affects nearly one in four children. It’s no wonder her favorite game growing up was playing doctor and patient.

Of course, she always insisted on being the doctor.

“Now lie down,” she’d order me with the authoritative tone she’d picked up from her own physicians. “Do you feel pain here? And here?” Her fingers would move expertly around my body.

“I’m so sorry, but I’ll have to give you a shot.” She’d pull a plastic syringe from the medical bag my parents had given her as a Christmas gift, lift it, carefully pump it until all bubbles were expelled, and jab me in the ass. “That wasn’t so bad now, was it?” She’d pat my shoulder, forgetting her own tears and screams whenever she had to get a shot.

I look at her as she lies in the hospital bed, a needle in her wasted arm, completely at ease. She's changed so much from the whimpering six-year-old who used to scream obscenities at the nurses whenever they tried to give her an injection. Gone are the days when she'd lock herself in the bathroom every afternoon when the town nurse, Maria, would come to our home to administer the daily shot of Desferal, a drug that helps her body eliminate the iron that accumulates in her organs because of the transfusions. Without it, she would eventually die of either heart or liver failure.

Now my sister administers her own shots. Pharmaceutical companies have designed a machine that releases the Desferal slowly over ten to twelve hours, thus eliminating most of the often-painful side effects. Every night, before she goes to bed, Simona sticks the needle in the muscle of her leg, secures the machine in place, and goes to sleep. All without shedding a tear.

Simona turns from her side to her back, making sure she doesn't tug on the needle in her left arm. With her right hand she frees the hair that got trapped under her shoulders. Her hair is brown and curly like mine, but that's where all similarities end. Her prominent cheekbones underscore beautiful almond-shaped eyes, giving her an almost exotic look that's typical of people affected with *Thalassemia*. She's the tallest in our family, with long slender legs and a shorter torso. Her breasts finally have filled out. She hasn't had a period yet—the disease again.

She's seventeen and about to complete a two-year bookkeeping certification program. Initially, when my mom insisted she should continue her studies, Simona resisted.

"What's the point?" Simona said while we were having lunch. "I'm going to die anyway."

"Don't talk like that." My mother glanced at my father, hoping to garner his support. But as with every meal we shared, my father stared at the TV blaring in the opposite corner of the dining room, oblivious to our conversation.

"And why not? You've said so yourself more than once."

"Treatment for your illness has improved over the years, and now that we live in Florence you have access to one of the best hospitals in Italy," my mom said. "What if you survive us? What are you going to do then? You need to plan for the future."

My sister put down her fork, wiped her lips with a napkin, and looked at my mother severely. "Mom, are you shitting me?" As usual, Simona could get away with language for which I was sure to get in trouble. Eventually she relented and registered in a trade school.

Funny how easily the rest of us take things for granted, like making long-term plans. We do it without even realizing. From "*Next summer I'll plant a vegetable garden*" to "*After the kids are grown, I'll go back to school*" and everything else in between. What would our lives be like without long-term plans? Can we even fathom a life without them?

My sister has no long-term plans.

She knows each day could be her last. She knows she won't live to be an old woman, to have children, or even be married. I wonder how that feels. Does she catch herself dreaming about the future and chide herself for slipping into the how-everyone-else-thinks mode?

The IV bag is still about one third full. I wonder how much longer we will be here, although it doesn't matter. I rather be here than at work. My sister follows my gaze.

"Sorry, it'll be at least three more hours. This blood flows so damn slow."

"It's okay. I know that. Any faster and it would put too much strain on your heart."

"Like that'd make a difference. I might look like a teenager on the outside, but if you had x-ray vision you'd think I was sixty years old. Sometimes I wonder why I even bother. You should take off."

"Don't worry. You're keeping me entertained."

Simona flashes me a grateful smile and goes on to tell another joke. She talks with her hands, her long slender fingers pirouetting in the air like conductors' batons.

A few months ago I finally got my driver's license, and this morning I'd volunteered to take her for her monthly transfusion. My mother was relieved—and so was Simona. I'm glad I can do this. It gives us the opportunity to spend time together, to get reacquainted. Even though we grew up together, we've led separate lives.

For the first five years of her life, before my parents discovered what was wrong with her, Simona cried non-stop. I resented her constant whimpering

and how I'd get in trouble if I caused her to cry by barely poking her with my finger. She was also spoiled rotten. While I got spanked for the tiniest infraction, she could cuss, talk back, and throw a tantrum with no consequences. When she was older, I wasn't allowed to play with her. Running, jumping, and wrestling were forbidden activities because her heart was too weak and her bones too brittle, and you can play only so many games of doctor and patient. It's different now. I'm twenty, she's seventeen. Being the fastest at playing hide-and-seek is no longer that important. We're getting to know each other. We're becoming friends.

Simona turns toward me, a mischievous smile on her lips. "Did I ever tell you about the time I met with the guidance counselor?"

Of course she had, more than once. "Mmm, I don't think you did."

"Well, I showed up at his office and he said, 'So, what are you planning to do once you graduate?' I looked at him and said, 'I have no plans. Haven't they told you? I'll be dead before I turn thirty.'" Simona laughs so hard she has to cross her legs, so she doesn't pee on the bed. "You should have seen his face—so red I thought it'd catch on fire."

The counselor did his best to salvage the meeting and his self-respect by offering the usual half-hearted, uninspired replies one always gives in a similar situation. "Oh, don't talk like that. I'm sure you'll live to be an old woman." Unable to regain his composure, he hastily concluded the appointment.

I laugh with her. Her humor has a brittle quality; one might even think she's cruel, but I know better. Sarcasm is her way to make light of the fact that every day she walks with death. Her humor is her way of keeping a step ahead of the voices—voices she has heard in the antiseptic hallways of hospitals, in doctors' waiting rooms, even in her parents' conversations. Voices that say her life is not worth living, that she's a burden and a sorrow, that it would have been better for her and everyone else had she not lived at all. I know she follows the statistics and the medical news that proudly announce the declining number of children affected by Thalassemia, that by whatever projected date this terrible disease—if everyone does their part—will be eradicated. That the way to eradication is for these children never to be born. That with early detection in this brave new world this is becoming a reality.

Part of her believes the voices. I know she does. Part of her believes that preparing for a career, going to school, trying to make friends is an exercise in futility. Sometimes the darkness wins.

"I'm going to commit suicide by oyster," she will tell me one day, a few years from this moment, before leaving on a trip to France.

"I ate fifty raw oysters in one sitting," she said when she returned, a defiant look in her eyes. I didn't take it personally. The defiant look was not directed at me. It was her way of looking death square in the eyes and saying, Clint Eastwood style, "Go ahead, make my day."

"Did you get sick?" I asked.

“Nope, not even a belly ache.” I thought I detected a faint note of disappointment in her voice.

The following year, she binged on alcohol while at a New Year’s Eve party. Another time, she ate seven large bowls of tomato bisque—her favorite. But death didn’t come.

I wonder what thoughts run through her mind when she lies alone in bed in the deep silences of the night, when there’s no one around to joke with, when the swoosh of the machine injecting another drop of medicine into her muscle is not loud enough to drown out those conceited, arrogant voices that tell her, “*you were a mistake.*” How does she fight the demons then?

I know that part of her is not persuaded. Part of her clings to the undeniable truth that her life matters. A truth only she knows, a truth reaffirmed by every breath she takes, every heartbeat, every laugh she draws.

I look at the IV bag. Still a couple of hours to go. I relax against the back of the chair and listen to Simona’s jokes. I chuckle. She looks at me, pleased. When we’re done, I’ll take her out for lunch. She loves that. We’ll take it slow on our way home.

My sister died eight years later from complications due to Thalassemia. She was twenty-five. At that time, she had found a job she loved. She worked for a company that trained her to teach mnemonic strategies. She’d get hired by schools, companies,

people with learning disabilities. Her job took her all over Italy. She loved helping others. She had also obtained her driver's license, bought a car—a hunter green secondhand Volkswagen—and was driving herself to the hospital once a month. She had even found love.

They had met at a party. It was love at first sight. He didn't care about her illness or that she could never have children. I met him for the first time at her funeral. He told me that he had been planning to propose.

I was not with her when she died, but I like to think that she was happy, that in the end the voice that said her life mattered had won. I like to believe that in the deep silences of the night she was making plans for the future.

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