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On Late-Stage Pediatric Cardiomyopathy

Should you find yourself coming-to while being wheeled out of high school pre-calculus, it is best not to open your eyes. You will get *that* feeling, the pressure of a return to consciousness, like breathing beneath a weighted blanket. Do not make eye contact with your peers in this state. Your guard will be down; someone perceptive might see your future flickering across your dilated pupils. Feign unconsciousness for a few more seconds, until the EMTs have turned the corner.

When you return to school later, make jokes about the “episode.” This will put your classmates at ease. They will give you terrible nicknames which they mean to be endearing. Accept these with a smile, internalize them, use them in reference to yourself—they are your only remaining link to the social order that was once so important.

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The problem with congestive heart failure is I sometimes forget I have it. I am seventeen, heart failure is a disease for old people, and I forget. I have good days, stretches where I breathe easy and walk at a regular pace. Then I go and do something stupid—bum half a

cigarette off my friend Benny behind the Dunkin' Donuts, try to chase the 37 bus, stand up too quickly—and end up back here.

At Memorial West, people know me. The ambulance driver calls ahead to let them know I'm coming, and the triage nurse high-fives me on the way in. A blistering pain ripples inside my ribcage when I move my arm, but I try not to flinch. Further down the hall, Igor, the janitor, updates me on the baseball scores. He's Ukrainian and can't pronounce his W's.

"Ey, Ven-dee, your Mets are heartbreakers this veek," he says.

"Leave Wendy alone," says the woman at Information. "She doesn't need your bad news."

"That's why I like them!" I call to Igor as I'm handed off to an orderly I've never met, who pushes me toward the elevators. But my voice shakes more than usual, and I don't know if he's heard me.

They take me straight to cardiology, where I am approximately fifty years younger than the average patient. They park my gurney alongside the nurses' station while they try to find me a room. A student tech lifts my shirt, affixing sticky electrodes up and down my torso, leaving my chest exposed, nipples prickling against the chill, sterile air. There was a point when I was ashamed of lying half-naked in public, but that seems like a long time ago now.

Behind the desk, Alisha is playing her perpetual game of Pac-Man on the computer she's supposed to use for medical records. For as many times as I've been here, I've never seen her pass the third level.

"That's cause these old people got me runnin' my ass all over this damn hospital," she says when I bring it up. She wags her head in the direction of the patient rooms, as if Pac-Man were her real job, and they were distracting her from it. She hushes my laughter. "Don't move! You'll mess up you EKG." It's only then I notice the familiar multicolored wires tentacling across my body and up to the computer. I quiet my breathing and wait while it graphs the jagged meter of my heart. The tech covers me with a gown and leaves. Alisha rips the accordion paper printout along its perforations, studies it, and calls my doctor over the loudspeaker.

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Like being an expert at anything, there are insider tricks for achieving an optimal hospital stay. If you are nice to an orderly, he will give you an extra pillow. If you make the nurses laugh, they will bring you ice chips and cans of ginger ale. If you humor the pediatric team, they will slip you hard candy under cover of secret handshakes. And there's the oxygen. Take it whenever it's offered, even if your breathing has steadied; you will get a buzz that plays nicely off any concoction already dulling your mind via the tube in the crook of your arm. Take hydromorphone whenever it's offered, too, even if you can stand the pain. It will fuck you up.

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"You're a cheap date," Doctor Kingston says, when he enters the OR as my irises bloom with pain medication. He used to be much more standoffish with me, but I have worn him down. Now he makes this joke every time he is about to cut me open, and I always laugh. My heart is not strong enough to hold up under general anesthesia, so they strap me to the table and numb me instead. Today they are draining fluid from my chest cavity to ease my breathing. It is one of many procedures Dr. Kingston and I have come to call "stall tactics" when no one else is around.

"I felt that," I say when I see his hand move to make the opening below my second rib.

"Did not," he says, but he clicks the pain med button once more, just in case. As he works I watch his eyes, wide and turquoise above his surgical mask. In these moments, I willfully misinterpret his kindness for the underpinnings of an epic romance.

"You're going to miss me," I slur, emboldened. Dr. Kingston has been trying to fix me for years, and I'm sometimes ashamed he'll have to count me among his failures.

"There," he says, sliding a small hose into the incision in my side. "That should help with the pressure." I feel something bubbling

inside me and the ceiling tiles swirl above my head. I squeeze my eyes shut.

He comes to check on me before he leaves for the day. Sighing, he cups my chin and presses on the wine-colored rings that have appeared beneath my eyes. I'd seen them, too, in the reflection of some glass on the way back to my room, but had been afraid to ask the nurse.

"What are they?" I say.

He is quiet.

"Just tell me."

"Your blood is pooling in concavities throughout your body as your circulatory system shuts down."

"Then what?"

"Drop in body temperature, fatigue. Loss of consciousness, depending on how stubborn you are." The ghost of a smile floats near the corner of his mouth. I smile back a little, too.

"So it won't hurt."

"Nope. This is probably the least painful part."

"How long?"

"Hard to say."

"Will you talk to my parents?"

"Always do, kiddo," he says.

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At this point, your family will be a sleep-deprived, overcaffeinated knot of tension, and it is best not to expect much of them. They will worry incessantly while trying not to worry you. They will build walls; they will suddenly believe in miracles. The sicker you get, the more their concern will manifest itself as a perfumed cloud of optimism. You may find it overbearing when they arrive and congregate around

your bed. They will talk relentlessly of a cure — a transplant, implant, or procedure they have researched online.

The doctor will come around, clipboard pressed into his hipbone, and talk statistics. He will use words like “hospice” and they will float right over your parents’ heads. Resist the urge to shake them. Let them have their miracles. They’ll have much more time to be sad about your dying than you will.

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My family arrives at dinnertime, their surplus adrenaline set loose via horseplay and shouting. I hear them down the hall at the nurses’ station and feel sorry for my roommate, who is nearly a century old and has only a thin gray curtain to insulate her from my impending visitors.

“What the fuck is that?” my sister says when she takes the corner into my room. Stella, at age thirteen, has the mouth of a motorcycle gangbanger. She points to the tube protruding through a slit in my gown and draining into a canister beside the bed.

“Don’t touch it!” I slap her hand away. “It’s attached!” Startled, she lurches backward into my father, throwing him off balance. He flails, backhanding my mother in the face, who then knocks the IV fluid from its hooked metal pole.

“Son of a—” My mother claps her hand over the red patch on her cheek.

“Jesus H. Christ on a stick!” My father catches the IV bag and reclasps it to its stand.

“Well shit,” Stella says, and runs back into the hall. I hear the rumble of the ice machine and know she is helping herself to soda and crackers from the storage closet.

“Yo Stella—you touching my stuff?” a nurse says as she passes.

“Hungry,” Stella calls back with her mouth full.

I watch my father scan the room. These first minutes, his eyes readjusting to the sight of his oldest child among the landscape of whirring medical machinery, are the only times he is overtly tender.

“Your lips are looking a little blue there, girlie,” he says. He sweeps my bangs aside to kiss my forehead, and I feel small again, safe with him towering above my bed.

“She’s fine,” my mother says. My father touches her arm, looks at her the way he does when he wants her to slow down. She leaves to find me an extra blanket, her brown pumps clacking on the linoleum.

It’s not that kind of cold, I want to say. Don’t you remember? The doctor said this would happen. Instead I reach for the playing cards Stella carries in her coat pocket. “Come on, guys,” I say.

Hours later, we’ve collectively finished off eight cafeteria grilled cheeses, my mother has dominated the card game, and my family is packing up for the night, gathering their backpacks and laptop cases. My father searches beneath the bed for the shoes he’s kicked off at some point in the evening. They promise to be back tomorrow upon completion of their daily responsibilities, which seem to occur on a plane of reality increasingly further away. My sister lingers in the doorway. Her face is sallow under the fluorescent track lighting, and I remember the bruises below my own eyes, the gathering blood that marks a turn in my condition.

“I wish you wouldn’t,” she says.

So do I, is another thing I don’t really say.

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Friendship at this stage is difficult, not because your friends are uncaring, but because you have changed. They may visit at first, call to check in, but you have unwittingly entered a long-distance relationship, and by the time you notice it, your momentum will be lost. Still there is the rare person with whom connections exist independently of time, the kind who can start a conversation one week and finish it another with nothing lost. This will be your final friend, more comforting than your family because he is not preoccupied with the unique horror of watching his own DNA dissipate. He will be a wreck when the time comes, but for now he is stable and willing to stick around as long as you do.

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Benny is the kind of kid who likes smoking not because he is addicted but because he's not supposed to do it. He comes to visit in the middle of the night because he gets off on breaking protocol. When I was in elementary school I'd slink up two floors to the pediatric oncology wing and have wheelchair races with the casualties of childhood cancer—I remember the thrill of navigating the deserted hallways without permission. So I leave Benny to his tiptoeing. I don't tell him the nurses would let him in anyway if I asked them to.

He slides into the shadows of my room as if he has been inching against the wall down the entire corridor, and I laugh picturing what must have been the most conspicuous sneaking in the history of visiting-hour breeches.

"Hey, creep," he whispers. "How's it going?" He kicks off his sneakers and lays down in my bed, squeezing himself against the bedrail. His fingers brush mine. "You're cold."

"I'm fabulous," I say.

"You're high." He averts his gaze from my lie, changes the subject. "Casey Walker got suspended for blowing Pete Hinds in the art room—in the kiln—yesterday."

"I miss all the good stuff."

"I missed you," he says, and leans in. I wish I had powdered away my black eyes.

"Me too," I say, mid-kiss. I like the way his lips stretch across mine when he smiles.

We have kissed in other places, under circumstances better than these—on the big hill in the state park, under the stairs in the science hallway—and I position myself among those backdrops now instead of here. We never bothered with the terminology of coupledness, though our friends have more than once declared us "together." Now I am glad we never really dated, never gave ourselves the opportunity to bicker and break up.

We talk about where we might apply to college, about how he'll be an eccentric architect and design us strange houses with too many staircases, or how, when we're really old, we'll meet on one another's stoops to take our daily walks. His eyes glow green like

traffic lights, and I let myself go, for a moment, into an existence where we are seventy and Benny smokes a pipe, our lives culminating in a series of completely unexceptional events. It is this world, the one I've not yet been to, that I will miss the most.

"It's okay, you know," Benny says before he leaves. His voice is smaller than usual.

"What?"

He stuffs his hands in his pockets, stares at his Vans. "To...not get better."

No one has ever said this out loud, and at first the words seem leaded, falling from my mind directly into my stomach. Then another feeling, a warmth welling up in my throat: relief.

"Thank you," I say, though I wish for something stronger.

In the darkest hours of the morning, I begin shivering. I try to stop. I focus on the little moan my roommate croaks out when she reaches through sleep for a deep breath. It doesn't help. I shake all over, and I don't know if it's from cold or fear.

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In the end, your body will know what to do. It will be methodical—a factory foreman adhering to procedure, the deliberate shutdown of systems. Do not panic. Do not micromanage. Try not to be bitter that your roommate is recovering and will go home tomorrow. It's not her fault you are sick.

Lie still. Wait for the light your friends from the cancer ward saw the nights you remained by their bedsides to see them through. If you can't find it, don't worry; it was probably just a reaction to the chemo, brain cells dissolving under the weight of poison and fatigue. As with our beginnings, there will rarely be anything extraordinary about the endings. Everyone will go eventually, some in this same bed. When you start to feel tired, close your eyes. It will be easier for everyone later, if they don't have to do it for you.

Pretend you are small and have been sent to bed early while the household remains lit and alive beneath you. The television will continue to flash; the refrigerator will engage its cyclical hum without you. Take solace in the fact that at least these things you're not seeing are commonplace. Submit to the weight of sleep. Allow yourself to believe you aren't missing anything.

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The sun's come up and the nurses are darting around my room, unplugging this and adjusting that, their rubber shoes squeaking as they spring from one machine to the next. They declare me unconscious. They yell to the receptionist to call my mother. I want to tell them they're moving much too quickly, that if they'd just slow down they'd notice the flit of my eyelashes, the twitch of my hand, and know I was still listening. But my eyelids hang heavy and my jaw feels disconnected, so I say nothing. I hear something familiar, the rattle of air pushing through faulty piping. I recognize it as a sound I've heard here before—a patient's breathing in her final hours—and realize it's resonating up from within me.

My family enters quietly. I know it's too early for them to be finished with their normal routines, that they've gotten the phone call and rushed over. This time I don't feel guilty for disrupting their schedules, am not irked by their desperate hopefulness. The scrape of wood against tile as they pull chairs close around my bed calms me.

They reminisce about things we used to do, then stop talking and take turns holding my hand. When I get Stella's, I squeeze it hardest, running my thumb against the tips of her unmarred fingers.

It is the first time I can remember all of them being completely silent. This, more than the coursing ache in my body, confirms the brevity of my time remaining.

I shuffle through mental archives, seeking something beautiful to fill these final moments. The ocean, Benny's and my first kiss, snow flurries in the days before Christmas. But everything I conjure up is interrupted by the schoolyard of my earliest childhood, and eventually I let the memory overtake me. The school, a dull brick box, sits atop a

hill. I stand on the edge of the playground, the space where the gravel and tar meet browning grass, my hands behind my back, fingers entwined in the fence that surrounds the property. A bell rings, signaling the end of recess, and my classmates dash up to the double doors of the school. As they run, they drop the red rubber dodgeballs they've been so enchanted with, and the balls roll down the slanted blacktop, a scarlet wave rushing toward chain-link.

Somewhere in the distance I hear the angry buzz of alarms. I watch the other children form neat lines and file back into the building. The dodgeballs recoil, expelling their final caches of energy, then rest motionless against the fence. I exhale.

SARA NOVIĆ is the author of *Girl at War* (Random House), which won an American Library Association Alex Award and has been translated into more than a dozen languages. Her next book, a collection of short biographies of American immigrants from all of the world's 195 countries, is forthcoming in 2019. She's an Assistant Professor of Creative Writing at Stockton University in New Jersey.