# **Five Feet Apart**

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#### For Alyson

#### -R. L.

We dedicate this book, and the movie, to all the patients, families, medical staff, and loved ones who bravely fight the battle against cystic fibrosis every day. We hope the story of Stella and Will helps to bring awareness to this disease and, one day, a cure.

—M. D. and T. I.

#### **CHAPTER 1**

### **STELLA**

I trace the outline of my sister's drawing, lungs molded from a sea of flowers. Petals burst out from every edge of the twin ovals in soft pinks, deep whites, even heather blues, but somehow each one has a uniqueness, a vibrancy that feels like it'll bloom forever. Some of the flowers haven't blossomed yet, and I can feel the promise of life just waiting to unfold from the tiny buds under the weight of my finger. Those are my favorites.

I wonder, all too often, what it would be like to have lungs this healthy. This *alive*. I take a deep breath, feeling the air fight its way in and out of my body.

Slipping off the last petal of the last flower, my hand sinks, fingers dragging through the background of stars, each pinpoint of light that Abby drew a separate attempt to capture infinity. I clear my throat, pulling my hand away, and lean over to grab a picture of us from off my bed. Identical smiles peek out from underneath thick wool scarves, the holiday lights at the park down the street twinkling above our heads just like the stars in her drawing.

There was something magical about it. The soft glow of the lampposts in the park, the white snow clinging to the branches of the trees, the quiet stillness of it all. We nearly froze our butts off for that picture last year, but it was our tradition. Me and Abby, braving the cold to go see the holiday lights together.

This photo always makes me remember that feeling. The feeling of going on an adventure with my sister, just the two of us, the world expanding like an open book.

I take a thumbtack and hang the picture next to the drawing before sitting down on my bed and grabbing my pocket notebook and pencil off my bedside table. My eyes travel down the long to-do list I made for myself this morning, starting with "#1: Plan to-do list," which I've already put a satisfying line through, and going all the way down to "#22: Contemplate the afterlife."

Number 22 was probably just a little ambitious for a Friday afternoon, but at least for now I can cross off number 17, "Decorate walls." I look around the formerly stark room I've spent the better part of the morning making my own, once again, the walls now filled with the artwork Abby's given me through the years, bits of color and life jumping out from clinical white walls, each one a product of a different trip to the hospital.

Me with an IV drip in my arm, the bag bursting with butterflies of different shapes and colors and sizes. Me wearing a nose cannula, the cable twisting to form an infinity sign. Me with my nebulizer, the vapor pouring out of it forming a cloudy halo. Then there's the most delicate one, a faded tornado of stars that she drew my very first time here.

It's not as polished as her later stuff, but somehow that makes me like it more.

And right underneath all that vibrancy is . . . my pile of medical equipment, sitting right next to a hideous green faux-leather hospital chair that comes standard for every room here at Saint Grace's. I eye the empty IV pole warily, knowing my first of many rounds of antibiotics over the next month is exactly an hour and nine minutes away. Lucky me.

"Here it is!" a voice calls from just outside my room. I look up as the door slowly creaks open and two familiar faces appear in the small crack of the doorway. Camila and Mya have visited me here a million times in the past decade, and they still can't get from the lobby to my room without asking every person in the building for directions.

"Wrong room," I say, grinning as a look of pure relief washes over them.

Mya laughs, pushing the door open the rest of the way. "It honestly could've been. This place is still a freaking maze."

"Are you guys excited?" I say, hopping up to give them both hugs.

Camila pulls away to look at me, pouting, her dark-brown hair practically drooping along with her. "Second trip in a row without you."

It's true. This isn't the first time my cystic fibrosis has taken me out of the running for some class trip or sunny vacation or school event. About 70 percent of the time, things are pretty normal for me. I go to school, I hang out with

Camila and Mya, I work on my app. I just do it all with low-functioning lungs. But for the remaining 30 percent of my time, CF controls my life. Meaning when I need to return to the hospital for a tune-up, I miss out on things like a class trip to the art museum or now our senior trip to Cabo.

This particular tune-up just happens to be centered around the fact that I need to be pumped with antibiotics to finally get rid of a sore throat and a fever that won't go away.

That, and my lung function is tanking.

Mya plunks down on my bed, sighing dramatically as she lies back. "It's only two weeks. Are you sure you can't come? It's our *senior trip*, Stella!"

"I'm sure," I say firmly, and they know I mean it. We've been friends since middle school, and they know by now that when it comes to plans, my CF gets the final say.

It's not like I don't want to go. It's just, quite literally, a matter of life or death. I can't go off to Cabo, or anywhere for that matter, and risk not coming back. I can't do that to my parents. Not now.

"You were the head of the planning committee this year, though! Can't you get them to move your treatments? We don't want you to be stuck here," Camila says, gesturing to the hospital room I so carefully decorated.

I shake my head. "We still have spring break together! And I haven't missed a spring break 'Besties Weekend' since eighth grade, when I got that cold!" I say, smiling hopefully and looking back and forth between Camila and Mya. Neither

of them returns my smile, though, and both opt to continue looking like I killed their family pets.

I notice they're both holding the bags of bathing suits I told them to bring, so I grab Camila's out of her hand in a desperate attempt to change the subject. "Ooh, suit options! We have to pick out the best ones!" Since I'm not going to be basking in the warm Cabo sun in a bathing suit of my choice, I figure I can at least live a little vicariously through my friends by picking out theirs with them.

This perks them both up. We eagerly dump their bags out on my bed, creating a mishmash of florals and polka dots and fluorescents.

I scan Camila's pile of bathing suits, grabbing a red one that falls somewhere between a bikini bottom and a single piece of thread, which I know without a doubt is a hand-medown from her older sister, Megan.

I toss it to her. "This one. It's very you."

Her eyes widen, and she holds it up to her waist, fixing her wire-frame glasses in surprise. "I mean, the tan lines would be pretty great—"

"Camila," I say, grabbing a white-and-blue-striped bikini that I can tell will fit her like a glove. "I'm kidding. This one's perfect."

She looks relieved, grabbing the bikini from me. I turn my attention to Mya's pile, but she's busy texting away from the green hospital chair in the corner, a big smile plastered on her face

I dig out a one-piece that she's had since swim class in sixth grade, holding it up to her with a smirk. "How's this, Mya?"

"Love it! Looks great!" she says, typing furiously.

Camila snorts, putting her suits back in the bag and giving me a sly smile. "Mason and Brooke called it quits," she says in explanation.

"Oh my god. They did not!" I say. This is news. *Amazing* news.

Well, not for Brooke. But Mya has been crushing on Mason since Mrs. Wilson's English class sophomore year, so this trip is her chance to finally make a move.

It bums me out I won't be there to help her make a killer ten-step "Whirlwind Cabo Romance with Mason" plan.

Mya puts her phone away and shrugs casually, standing and pretending to look at some of the artwork on the walls. "No big deal. We're going to meet him and Taylor at the airport tomorrow morning."

I give her a look and she breaks out into a huge smile. "Okay, it's a little bit of a big deal!"

We all squeal with excitement, and I hold up an adorable polka-dot one-piece that is super vintage, and right up her alley. She nods, grabbing it and holding it up to her body. "I was *totally* hoping you'd pick this one."

I look over to see Camila glancing at her watch nervously, which is no surprise. She's a champion procrastinator and probably hasn't packed a single thing for Cabo yet.

Besides the bikini, of course.

She sees me notice her checking her watch and grins sheepishly. "I still need to buy a beach towel for tomorrow."

Classic Camila.

I stand up, my heart sinking in my chest at the thought of them leaving, but I don't want to hold them up. "You guys have to get going, then! Your plane is at, like, the ass crack of dawn tomorrow."

Mya looks around the room sadly while Camila twists her bag of suits dejectedly around her hand. The two of them are making this even harder than I thought it would be. I swallow the guilt and annoyance that come bubbling up. It's not like they're the ones missing their senior trip to Cabo. At least they'll be together.

I give them both big smiles, practically pulling them to the door with me. My cheeks hurt from all this fake positivity, but I don't want to ruin it for them.

"We'll send you a bunch of pictures, okay?" Camila says, giving me a hug.

"You'd better! Photoshop me into a few," I say to Mya, who is a wizard at Adobe. "You won't even know I wasn't there!"

They linger in the doorway, and I give them an exaggerated eye roll, playfully shoving them out into the hallway. "Get outta here. Go have a great trip."

"Love you, Stella!" they call as they walk down the hallway. I watch them go, waving until Mya's bouncing curls are completely out of sight, suddenly wanting nothing more than to be walking out with them, off to pack instead of unpack.

My smile fades as I close the door and see the old family picture pinned carefully to the back of my door.

It was taken a few summers ago on the front porch of our house during a Fourth of July barbecue. Me, Abby, Mom, and Dad, goofy smiles on all our faces as the camera captures the moment. I feel a swell of homesickness as I hear the sound of the worn, rickety wood of that front step, creaking underneath us as we laugh and get close for the picture. I miss that feeling. All of us together, happy and healthy. For the most part.

This isn't helping. Sighing, I pull myself away, looking over at the medicine cart.

In all honesty, I like it here. It's been my home away from home since I was six, so I usually don't mind coming. I get my treatments, I take my medicine, I drink my body weight in milk shakes, I get to see Barb and Julie, I leave until my next flare-up. Simple as that. But this time I feel anxious, restless even. Because instead of just wanting to get healthy, I *need* to get healthy. For my parents' sake.

Because they've gone and messed up everything by getting divorced. And after losing each other, they won't be able to handle losing me, too. I know it. If I can get better, maybe . . .

One step at a time. I head over to the wall oxygen, double-checking the flowmeter is set properly, and listen for the steady hiss of the oxygen coming out of it before I pull the tube around my ears and slide the prongs of the cannula into my nose. Sighing, I sink down onto the familiarly uncomfortable hospital mattress, and take a deep breath.

I reach for my pocket notebook to read the next thing on my to-do list and keep myself preoccupied—"#18: Record a video."

I grab my pencil and bite it thoughtfully as I stare at the words I wrote earlier. Oddly enough, contemplating the afterlife seems easier right now.

But the list is the list, so, exhaling, I reach over to my bedside table to get my laptop, sitting cross-legged on the new floral comforter I picked out yesterday at Target while Camila and Mya were buying clothes for Cabo. I didn't even need the comforter, but they were so enthusiastic in helping me pick something out for my trip to the hospital, I felt bad not getting it. At least it sort of matches my walls now, bright and vibrant and colorful.

I drum my fingers anxiously on the keyboard, and squint at my reflection in the screen while my computer starts up. I frown at the mess of long brown hair and try to smooth it down, running my fingers through it over and over. Frustrated, I pull my hair tie off my wrist and resort to a messy bun in an attempt to look halfway decent for this video. I grab my copy of *Java Coding for Android Phones* off

my bedside table and put my laptop on top of it, so I don't show some serious under chin, and can have a shot that's remotely flattering.

Logging on to my YouTube Live account, I adjust the webcam, making sure you can see Abby's lung drawing directly behind me.

It's the perfect backdrop.

I close my eyes and take a deep breath, hearing the familiar wheeze of my lungs trying desperately to fill with air through the sea of mucus. Exhaling slowly, I slap a big Hallmark-greeting-card smile on my face before opening my eyes and pressing the enter key to go live.

"Hey, guys. Is everyone having a good Black Friday? I waited for snow that never came!"

I glance into the corner of my screen as I turn the camera toward the hospital window, the sky a cloudy gray, the trees on the other side of the glass completely barren. I smile as my livestream count goes steadily past 1K, a fraction of the 23,940 YouTube subscribers who tune in to see how my battle with cystic fibrosis is going.

"So, I could be getting ready to go on a plane to Cabo for my school's senior trip, but instead I'll be spending this holiday at my home away from home, thanks to a mild sore throat."

Plus, a raging fever. I think back to when I got my temperature taken on intake this morning, the flashing numbers on the thermometer blaring out a strong 102. I don't

want to mention it in the video, though, because my parents will definitely be watching this later.

As far as they know, I just have a nagging cold.

"Who needs two whole weeks of sunshine and blue skies and beaches when you can have a month of luxury right in your own backyard?"

I rattle off the amenities, counting them on my fingers. "Let's see. I've got a full-time concierge, unlimited chocolate pudding, and laundry service. Oh, and Barb talked Dr. Hamid into letting me keep all my meds and treatments in my room this time! Check it out!"

I turn the webcam to the pile of medical equipment and then to the medicine cart next to me, which I've already perfectly organized into alphabetical *and* chronological order by the scheduled dosage time I plugged into the app I made. It's *finally* ready for a test run!

That was number 14 on today's to-do list, and I'm pretty proud of how it turned out.

My computer dings as comments begin rolling in. I see one mentioning Barb's name with some heart emojis. She's a crowd favorite just as much as she's my favorite. Ever since I first came to the hospital more than ten years ago, she's been the respiratory therapist here, slipping candy to me and the other CFers, like my partner in crime Poe. She holds our hand through even the most bone-crushing grips of pain like it's nothing.

I've been making YouTube videos for about half that time to raise awareness about cystic fibrosis. Through the years more people than I could have ever imagined began following my surgeries and my treatments and my visits to Saint Grace's, sticking with me through my awkward braces phase and everything.

"My lung function is down to thirty-five percent," I say as I turn the camera back to me. "Dr. Hamid says I'm steadily climbing to the top of the transplant list now, so I'll be here for a month, taking antibiotics, sticking to my regimen . . . ." My eyes travel to the drawing behind me, the healthy lungs looming over my head, just out of reach.

I shake my head and smile, leaning over to grab a bottle from the medicine cart. "That means taking my medications on time, wearing my AffloVest to break up that mucus, and"—I hold up the bottle—"a whole lot of this liquid nutrition through my G-tube every night. If any ladies out there are wishing they could eat five thousand calories a day and still have a Cabo-ready beach body, I'm up for a trade."

My computer dings away, messages pouring in one after another. Reading a few, I let the positivity push away all the negativity I felt going into this.

Hang in there, Stella! We love you.

Marry me!

"New lungs can come in *at any moment*, so I've got to be ready!" I say the words like I believe them wholeheartedly.

Though after all these years I've learned to not get my hopes up too much.

DING! Another message.

I've got CF and you remind me to always stay positive. XOXO.

My heart warms, and I give a final big smile for the camera, for that person fighting the same fight that I am. This time it's genuine. "All right, guys, thanks for watching! Gotta double-check my afternoon and evening meds now. You know how anal I am. I hope everyone has a great week. Bye!"

I end the live video and exhale slowly, closing the browser to see the smiling, winter-formal-ready faces on my desktop background. Me, Camila, and Mya, arm in arm, all in the same deep-red lipstick we'd picked out together at Sephora. Camila had wanted a bright pink, but Mya had convinced us that red was the color we NEEDED in our life. I'm still not convinced that was true.

Lying back, I pick up the worn panda resting on my pillows and wrap my arms tightly around him. Patches, my sister, Abby, named him. And what a fitting name that became. The years of coming in and out of the hospital with me have certainly taken their toll on him. Multicolored patches are sewn over spots where he ripped open, his stuffing pouring out when I squeezed too hard during the most painful of my treatments.

There's a knock on my door, and it flies open not even a second later as Barb busts in holding an armful of pudding cups for me to take my medication with. "I'm back! Delivery!"

When it comes to Barb, not much has changed in the past six months, or the past ten years for that matter; she's still the best. The same short, curly hair. The same colorful scrubs. The same smile that lights up the entire room.

But then an extremely pregnant Julie trails behind her, carrying an IV drip.

Now that's a big change from six months ago.

I swallow my surprise and grin at Barb as she places the pudding at the edge of my bed for me to sort onto my medicine cart, then pulls out a list to double-check that the cart has everything I need on it.

"What would I do without you?" I ask.

She winks. "You'd die."

Julie hangs the IV bag of antibiotics next to me, her belly brushing up against my arm. Why didn't she tell me she's pregnant? I go rigid, smiling thinly, as I eye her baby bump and try to subtly move away from it. "A lot's changed in the past six months!"

She rubs her belly, blue eyes shining brightly as she gives me a big smile. "You want to feel her kick?"

"No," I say, a little too quickly. I feel bad when she looks slightly taken aback at my bluntness, her blond eyebrows arching up in surprise. But I don't want any of my bad juju near that perfect, healthy baby.

Luckily, her eyes travel to my desktop background. "Are those your winter formal pics? I saw a bunch on Insta!" she says, excited. "How was it?"

"Super fun!" I say with a ton of enthusiasm as the awkwardness melts away. I open a folder on my desktop filled with pictures. "Crushed it on the dance floor for a solid three songs. Got to ride in a limo. The food didn't suck. Plus, I made it to ten thirty before I got tired, which was way better than expected! Who needs a curfew when your body does it for you, right?"

I show her and Barb some pictures we all took at Mya's house before the dance while she hooks me up to the IV drip and tests my blood pressure and O<sub>2</sub> reading. I remember I used to be afraid of needles, but with every blood draw and IV drip, that fear slowly drifted away. Now I don't even flinch. It makes me feel strong every time I get poked or prodded. Like I can overcome anything.

"All righty," Barb says when they get all my vitals and finish oohing and aahing over my sparkly, silver A-line gown and my white rose corsage. Camila, Mya, and I decided to swap corsages when we went stag to the formal. I didn't want to take a date, not that anybody asked me anyway. It was super possible that I would need to bail the day of, or wouldn't feel well halfway through the dance, which wouldn't have been fair to whomever I could've gone with. The two of them didn't want me to feel left out, so instead of getting dates of their own, they decided we'd all go together.

Because of the Mason developments, though, that doesn't seem super likely for prom.

Barb nods to the filled medicine cart, resting a hand on her hip. "I'll still monitor you, but you're pretty much good to go." She holds up a pill bottle. "Remember, you *have* to take this one with food," she says, putting it carefully back and holding up another one. "And make sure you don't—"

"I got it, Barb," I say. She's just being her usual motherly self, but she holds up her hands in surrender. Deep down she knows that I'll be absolutely fine.

I wave good-bye as they both head toward the door, using the remote next to my bed to sit it up a little more.

"By the way," Barb says slowly as Julie ducks out of the room. Her eyes narrow at me and she gives me a gentle warning look. "I want you to finish your IV drip first, but Poe's just checked in to room 310."

"What? Really?" I say, my eyes widening as I move to launch myself out of bed to find him. I can't believe he didn't tell me he'd be here!

Barb steps forward, grabbing my shoulders and pushing me gently back down onto the bed before I can fully stand. "What part of 'I want you to finish your IV drip first' did you not get?"

I smile sheepishly at her, but how could she blame me? Poe was the first friend I made when I came to the hospital. He's the only one who really gets it. We've fought CF together for a freaking decade. Well, together from a safe distance, anyway.

We can't get too close to each other. For cystic fibrosis patients, cross-infection from certain bacteria strains is a huge risk. One touch between two CFers can literally kill the both of them

Her serious frown gives way to a gentle smile. "Settle in. Relax. Take a chill pill." She eyes the medicine cart, jokingly. "Not literally."

I nod, a real laugh spilling out, as a fresh wave of relief fills me at the news of Poe being here too.

"I'll stop by later to help you with your AffloVest," Barb says over her shoulder as she leaves. Grabbing my phone, I settle for a quick text message instead of a mad dash down the hall to room 310.

You're here? Me too. Tune-up.

Not even a second goes by and my screen lights up with his reply: Bronchitis. Just happened. I'll live. Come by and wave at me later. Gonna crash now.

I lean back on the bed, exhaling long and slow.

Truth is, I'm nervous about this visit.

My lung function fell to 35 percent so quickly. And now, even more than the fever and the sore throat, being here in the hospital for the next month doing treatment after treatment to stem the tide while my friends are far away is freaking me out. A lot. Thirty-five percent is a number that keeps my mom

up at night. She doesn't say it, but her computer does. Search after search about lung transplants and lung-function percentages, new combinations and phrasing but always the same idea. How to get me more time. It makes me more afraid than I've ever been before. But not for me. When you have CF, you sort of get used to the idea of dying young. No, I'm terrified for my parents. And what will become of them if the worst does happen, now that they don't have each other.

But with Poe here, someone who *understands*, I can get through it. Once I'm actually allowed to see him.

\* \* \*

The rest of the afternoon goes by slowly.

I work on my app, double-checking that I worked out the programming error that kept coming up when I tried to run it on my phone. I put some Fucidin on the sore skin around my G-tube in an attempt to make it less fire-engine red and more of a summer-sunset pink. I check and double-check my "At Bedtime" pile of bottles and pills. I reply to my parents' every-hour-on-the-hour texts. I gaze out the window as the afternoon fades and see a couple about my age, laughing and kissing as they walk into the hospital. It's not every day you see a happy couple coming into a hospital. Watching them holding hands and exchanging longing glances, I wonder what it would be like to have somebody look at me like that. People are always looking at my cannula, my scars, my Gtube, not at me.

It doesn't make guys want to line up by my locker.

I "dated" Tyler Paul my freshman year of high school, but that lasted all of a month, until I came down with an infection and needed to go to the hospital for a few weeks. Even just a few days in, his texts started to get further and further apart, and I decided to break up with him. Besides, it was nothing like that couple out in the courtyard. Tyler's palms were sweaty when we held hands, and he wore so much Axe body spray, I would go into coughing fits every time we hugged.

This thought process is not exactly a helpful distraction, so I even give number 22, "Contemplate the afterlife," on my todo list a try, and read some of *Life, Death, and Immortality: The Journey of the Soul.* 

But, pretty soon, I opt to just lie on my bed, looking up at the ceiling and listening to the wheezing sound of my breathing. I can hear the air struggling to get past the mucus that takes up space in my lungs. Rolling over, I crack open a vial of Flovent to give my lungs a helping hand. I pour the liquid into a nebulizer by my bed, the small machine humming to life as vapors pour from the mouthpiece.

I sit, staring at the drawing of the lungs while I breathe in and out.

And in and out.

And in and . . . out.

I hope when my parents come to visit over the next few days, my breathing is a little less labored. I told them both that the other one was taking me to the hospital this morning, but I actually just took an Uber here from the corner a street over from my mom's new place. I don't want either of them to have to face seeing me here again, at least until I'm looking better

My mom was already giving me troubled looks when I needed to put my portable oxygen on just to pack.

There's a knock on my door, and I look over from the wall I'm staring at, hoping it's Poe stopping by to wave at me. I pull the mouthpiece off as Barb pops her head in. She drops a surgical face mask and latex gloves onto a table next to my door.

"New one upstairs. Meet me in fifteen?"

My heart leaps.

I nod, and she gives me a big smile before ducking out of the room. I grab the mouthpiece and take one more quick hit of the Flovent, letting the vapor fill my lungs the best I can before I'm up and moving. Shutting the nebulizer off, I pick up my portable oxygen concentrator from where it's been charging next to my bed, press the circular button in the center to turn it on, and pull the strap over my shoulder. After I put the cannula in, I head over to the door, pulling on the blue latex gloves and wrapping the strings of the face mask around my ears.

Sliding into my white Converse, I push my door open then squeeze out into the whitewashed corridor, deciding to go the long way so I can walk past Poe's room.

I pass the nurses' station in the center of the floor, waving hello to a young nurse's assistant named Sarah, who is