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Chapter 1 of “Gloria and Ellen”

It is a lovely Indian summer day, the kind that makes the freezing Buffalo winters totally worth it. With a lot of coaxing and cajoling, we managed to convince both our teenagers to come out sailing. Mark at fourteen thinks spending any time at all with his family is an unbearable indignity, so Brian bribed him with extra gaming time. Betsy, as always, came obediently, but she looked tired. Over the summer, she'd taken to sleeping late into the afternoon, but it's hard to know if that's normal sixteen-year-old behavior or yet another side effect of her weak heart.

Hopefully the fresh air and being out on Lake Erie will cheer us all up. Brian has been so edgy lately, things at work aren't going well, and I feel exhausted and perimenopausal all the time.

Glancing over at Betsy as I start pulling picnic supplies out of the hamper, getting ready for lunch, I see she looks paler than usual. I feel my heart lurch, but out of long habit, calm myself so I sound perfectly natural and unalarmed.

“You okay, Bets?” I call out, passing the Tupperware box of devilled eggs to her, then handing the box of carrot and celery sticks with peanut butter to Mark.

I pop open a beer for Brian and pass it to him, then slide my eyes back to Betsy.

“I'm fine, Mom,” she says, her resigned and weary tone belying her words.

I catch Brian's eye and send him the telepathic message we have become so practiced at delivering, that says, Uh oh, I'm worried, is she OK?

Mark rolls his eyes. “Could I have one of those eggs too, Bets, if you're not too tired to pass them this way?”

Betsy glares at him, but passes the box across. “Can I have a Ginger Ale please, Mom?”

Cola drinks are bad for your heart, so the only soda pop I allow is Ginger Ale, and we only have it rarely, like for drinks on special occasions or when we're out on the boat.

I pull a Ginger Ale out of the cooler and pass it to Betsy, smiling encouragingly at her, then quickly hand one to Mark too when I see his scowl. He's slouched next to Brian, they're deep in conversation about internal combustion engines. He's wearing his raggedy Rolling Stones t-shirt and his everlasting Buffalo Bills baseball cap, and looks so scruffy I can't bear to think what they'll say when we dock back at the Buffalo Yacht Club.

Fortunately, Brian looks as casually elegant as always, standing at the helm, his Docksidereed feet akimbo, his blue button-down shirt with the sleeves rolled up, his madras Bermuda shorts held up by the blue and white whale belt Mark gave him for his last birthday. The wind barely musses his short brown hair. It's unfair that he just has a hint of white at the temples, when he's six years older than I am. I'd be salt-and-pepper all over if it weren't for my monthly visits to the salon.

Lunch progresses, the sun is warm, the breeze is strong enough that we move right along but not so strong that I feel like I have to grip the gunwale. Mark takes a turn at the helm while Betsy lies down on the bow deck, sunglasses firmly in place so I can't read her expression.

Wispy white caps are starting to appear, so we've come about, getting ready to head back when Betsy sits up, and tugs the sleeve of my light cotton sweater.

Turning quickly, I go through my mental checklist. Betsy's former pallor has turned ever so slightly blue and her breathing, which had been fine all day, is coming in shorter, shallow gulps.

Quietly, I say to Brian, “Honey, let's get the sails down and the motor on. We need to get in.”

Brian looks quickly at Betsy, then at me, then jumps into action.

Pointing the ketch into the wind, he says, “Mark, I've got the jib, you get the mainsail.”

The jib is self-furling, but I help Mark furl the mainsail while Brian starts the engine and opens the throttle, setting a straight course for the Yacht Club. While Mark puts out the rubber bumpers, I pack the last of the picnic things. I make sure I have my purse and Betsy's things, shooting quick looks at her slumped forward in the cockpit, elbows on her knees.

As Brian maneuvers us expertly into our slip, I say, “I'll take Betsy. Can you guys get home on your own?”

“Sure, honey.” Then he holds Betsy's elbow as she steps across the gunwale onto the dock.

“You take care, Bets. See you tonight - make sure you're home for Madam Secretary tonight!”

Betsy and I leave Brian and Mark stowing gear, Mark grumbling and looking sullen and grumpy, and make our way to the parking lot.

I wave quickly at the Thompsons, who are coming out of the clubhouse, but turn away so we don't have to have a conversation. She'll make some comment to Brian about what a rush I'm always in, but Amy Thompson loves the sound of her own voice and can keep you standing listening to her talk for hours.

We get into my dark blue Prius and I drive quickly up Porter to Symphony Circle, then straight on North to Buffalo General. From long habit, I call ahead on the hands-free so Betsy's cardio team will be ready to meet us, all the while shooting quick glances at Betsy.

I focus on not saying any of the things that are racing through my mind: How long have you been feeling weaker? Why didn't you tell me? Did you not say anything on purpose? Are you depressed? Oh my god, why didn't I notice earlier? Please please please let her be alright, I'll do anything if you'll just let her be alright. Why haven't those people at UNOS found her a heart yet? Why is the van in front of me driving so slowly, are they idiots or something? Really? Now is the time to pull out of that parking spot at 0 miles an hour? Get out of my way! My daughter may be dying! My jaw actually aches from not moving.

Betsy is sitting back in the warm tan leather passenger seat, her windbreaker pulled on quickly over her pink One Direction t-shirt, her scruffy Dockers braced on the dashboard. Her breathing is, as my nursing training would describe it, short and labored. Her lips are pink-blue, a sign of cyanosis and a strong indicator that her congenital heart defect, that has plagued her since birth, is acting up, as usual.

As a big SUV backs out, I cut in front of a VW and pull into a parking spot right by the front entrance, ignoring the VW driver's angry honking, and bustle over to Betsy's side to help her out. Alejandro, one of our favorite orderlies, wheels a wheelchair over to the curb and helps Betsy into it, keeping up a light flow of cheerful small talk about the weather and the Bills game he'd been to see last Thursday (he and Betsy are both football fans, albeit not at the same level of intensity). His voice is deep and soothing, and I can actually feel the muscles in my neck and shoulders start to relax as he chuckles at something Betsy says. He looks like a young James Earl Jones, and we all really like him. He's studying to get his RN, so he and I often talk about his homework assignments and where he wants to work.

Betsy by now is limp and grey, so Alejandro moves quickly through the maze of corridors, beating a very familiar path to the cardio area. Betsy's team jumps in when we come through the swinging doors, and with a squeeze of my daughter's limp, frail hand, I step back to let them go to work.

"I love you, Bets!" I call after her. "I'll be right in once I've got everything filled out."

Betsy doesn't respond, and I feel a horrible tightening in my chest. Sometimes I picture reaching into my own forty-five-year-old chest and ripping out my heart to give to Betsy. She's been on the UNOS list since she was eleven, but we've had a lot of trouble finding a match. One had raised our hopes dramatically, only to fall through when the donor family changed their mind at the last minute (Betsy was thirteen, and had already been prepped and everything, and when we got the news, I was so angry I frightened myself).

Since she was born, I've lost count of the operations and procedures and medications we'd tried. Nothing seems to work for long, but the last round seemed to do better, and we'd been so hopeful. It's been almost a year since Betsy has had what they irritatingly called an incident. It's not an incident! I want to yell, it's a never-ending nightmare!

Standing at the intake station waiting for the forms to sign, I click the ballpoint pen over and over until the nurse finally looks up pointedly. Finally, I scribble my name then grab my bag and race to where I last saw Betsy going.

Alejandro is just coming out pushing the empty wheelchair. "They're taking her into surgery, they think the stent may have moved. Dr. Renkiewicz is there, though - she'd just come in to check on a patient - so Betsy's in great hands."

I can literally feel my blood stopping, and Alejandro reaches out a steadying hand. "Whoa there! You want to sit down?" He turns the wheelchair toward me.

Mutely, I shake my head, not sure I won't burst into tears, trying to remember the drill, breathe deeply and slowly, focus on your breathing, let the thoughts and feelings come in but then gently push them away.

Alejandro guides me to one of the blue sofas in the waiting area, and sits down next to me. His big warm hand on my arm is very comforting, and I glance up at him to let him know how grateful I am, but instead I feel a gasp burst out of me and water starts pouring down my face.

"Hey, it's OK. Just let it out. Keep taking those deep breaths. I'm right here."

I feel mucus start to drip out of my nose as huge wracking sobs finally break out. Fortunately, the waiting room is empty - Sunday evening in the cardio lounge. Alejandro passes me one of those little packets of tissues with the little restickable tab, but I can't seem to open it, so he takes it back, opens it and hands me a tissue. I blow my nose noisily, gulping for air, and blow again, the tissue no match for my crying. Alejandro hands me another one, and I blow again, feeling the first horrible wave of shock and fear start to recede slowly.

"I'm so sorry, Alejandro," I mutter, pulling out another tissue and drying my eyes and neck, where the tears have dripped all the way to my shirt.

"No problem, you know it's all in a day's work. Besides, you're my favorite patient's mom!"

I smile in a watery way and sit back, exhausted and drained. And as usual, gripped by anxiety.

"But you're right," I say, continuing the conversation in my head out loud, "Dr. Renkiewicz is one of the best, if not THE best. So she's in great hands." I find myself nodding, trying to reassure and convince myself.

"That's right, she is. And you know Betsy's a fighter. She's pulled through worse before so..."

Nodding again, I agree. "Did she say how long... or anything else?" I know the drill well enough to know that I have hours of waiting and worrying ahead of me, but that doesn't stop me from grasping for any little bit of extra information that could restore to me at least the illusion of participating, of knowing what's going on.

"She just asked me to tell you that she would let us know as soon as she knows anything."

That's the party line, and I've been around the block enough times to know that, but I appreciate his trying, so squeeze his hand. "Thanks for being there, Alejandro."

"Anytime, you know that."

"And thanks for all these tissues, where would we be without you?"

He smiles, but then stands up when his beeper goes off. "I gotta get back to my shift. You want me to bring you a coffee or anything?"

"No, I've got this down pat, but thanks. I'll get a coffee later. I've got to call Brian now."

I fumble in my bag then realize I left my cell phone in the car, so have to go all the way back out to the entrance to get it. Guiltily, I see there are two missed calls from Brian, so I dial him quickly.

He picks up right away. "My god, Ellen, why didn't you pick up? Is Betsy OK?"

Feeling the tears welling up again, I plonk into the front seat and turn the car and its AC on. The anxiety has brought on a cascade of hot flashes, and the already warm September evening seems stifling.

I tell him what I know, blowing my nose and wiping my tears and feeling a tight headache form behind my eyes.

"Where are you guys now?"

"We got a lift from the Thompsons."

I groaned.

"I know, but they were actually very nice about it. I think they live somewhere in Snider, so it was sort of on their way, but still, they brought us all the way home. And Amy didn't even talk the whole way, Bruce actually got a word in, and asked us how we were doing."

I'm too tired and anxious to laugh. "Did you have any supper? How's Mark?"

"Yes and fine. I heated up the M&C from yesterday's lunch and we ate it together. He didn't lift his eyes from his phone the whole time, and now is upstairs. I said he could play Runescape until bedtime, and that I'd come up and check at 10, but lights out at 11."

"But you know Dr. Blasdel said he shouldn't play right before bed!" I rub my temples and try covering my eyes. This isn't Brian's fault, and we had said Mark could game tonight. I take a deep breath.

"I know, honey. But we said he could, and honestly, I think this stuff with Betsy is just so hard on him. I didn't have the heart to say No." Then hastened to add, "No pun intended..." (I hate it when he puns).

"I know. And I know it's tough, and I know we said he could, just tonight. But please don't make me be the bad guy all the time."

"I won't, Ellen. I know. Anyway, for now we need to focus on Betsy. Should I come to the hospital now?"

"No, let's just wait for a while. I have my needlepoint in the car, so I'm going to go get a sandwich and a cup of coffee and I'll sit in the lounge there. I'll call as soon as there's news, or by 11pm at the latest."

"Okay, if that's what you want. I'm happy to come though if you need me...."

I wish Brian wouldn't ask if I want him to do something and instead would just go ahead and do it. But I did just say not to come. And he really doesn't need to be here. Sometimes I feel like I'm going nuts. Thinking about that brings a flush of heat, so I hang up and turn up the AC, the freezing air drying my face and leaving a stiff, salty feeling.

Wearily, I get out of the car, get my needlepoint bag out of the trunk, and trundle back into the hospital. Fortunately hospital food has come a long way since Betsy was a baby, so instead of burned rock gut I actually have a delicious cup of coffee, some Kenyan medium roast, and a piece of ciabatta with sun dried tomatoes and goat cheese that they heated up in the little oven, not in a microwave, so the bread didn't get all soggy. Feeling a lot better, I go to the Ladies' room and wash the remnants of the tears off of my face, putting on a little of the Pourquoi Pas lipstick I bought last week at Macy's at the Walden Galleria. Betsy and I went together for some mom-and-daughter time, and we'd both had makeovers. I smile at the memory of Betsy's face made up. She was so pretty she really didn't need any makeup, but we got a good sales person, who really knew her stuff, and at the end, Betsy looked radiant. Of course, it all came off that night using the expensive makeup remover they'd also sold us, along with a full set of foundation, blush, eyeshadow and liner, mascara and lipstick/gloss for each of us. But for a little while, it felt like we were just a normal mother and daughter, out for a fun coming-of-age ritual.

I know from experience that if the stent that they'd put in a year ago has moved that I'm likely to be here for at least a few hours, and that Betsy will likely be in the hospital for a couple or three days. Of course this WOULD happen right after the school year started, when all the cliques are forming again. But I push those thoughts away, along with the irritation they cause.

I go back to the waiting room with my coffee and my needlepoint, and mentally follow along with the operation. Betsy would be anesthetized, and shaved, and they'd connect an IV drip, then Dr. Renkiewicz would insert a catheter into the blood vessel in her groin, through a small cut. When Betsy was little, this was a lot scarier, but they'd made such huge strides forward that I know enough not to be panicking just yet.

So I sit there, working on a cover of a small throw pillow for the sofa in the living room. I made the design myself, a riot of intertwined flowers and vines, and I'm about halfway through it.

Then almost at 11pm, as I'm getting ready to call Brian, Dr. Renkiewicz comes into the waiting room, looking serious and unhooking the surgical mask from behind her ears as she comes.