

## Swan Song

Stephanie R. deLusé, PhD

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*From the backdrop of one night's main event, the author weaves together music, memories, and people to explore complex family and religious dynamics. Family secrets and tender appreciations surface at the "bon voyage" party of a young man departing life too soon.*

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It is hard to make the calls, challenging to keep my voice steady, but it has to be done. I don't want to face it; explaining the circumstances to people and their message machines seems surreal to me, but the time has drawn too near to deny it anymore.

"Hello, Aunt Joyce? Please come to Jeff's tonight. And tell Will and the girls. Jeff's asking that everyone come to a celebration of sorts. We'd all love to see you—especially Jeff," I say as I call another relative at the bidding of my 42-year-old brother.

"Hello, Uncle Von? Can you and Aunt Mary make yourselves available tonight? I know it is last-minute, but it's important. . ."

And so the calls went, one after another, as the lists of yes, no, and maybe responses grew. It was such short notice, we knew, but my fading brother had called for his fans—or so they seemed to me—to form an audience. Given the occasion, I truly hoped he'd get a good one. As his curtain call approaches, he wants us all to be there.

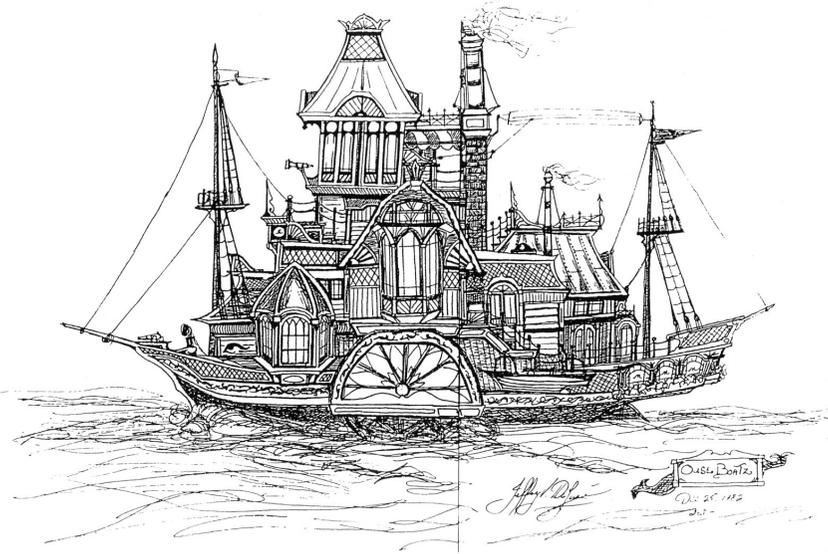
I am at Jeff's house, helping with the preparations. My cousin Janice and I twist together vibrant-colored crepe paper, tottering as we balance on odd pieces of antique furniture to pin the streamers and balloons high to the ceiling and walls. I cry. Jeff's friend Richie arrives with coolers of ice and cases of beverages; we numbly tuck cans and bottles between frosty cubes, sighing smiles at our faulty attempts at small talk. Janice tries not to cry. Jeff suddenly worsens and we fear he will leave us even before the party begins. The paramedics pull up, lights and sirens in full force; they storm through our nascent party scene to leave only minutes later, without Jeff. A premature alarm. The "DNR—Do Not Resuscitate" order taped to the fridge ties their hands, and Jeff isn't quite ready to leave. I guess we shouldn't have even called them, but it can be hard to tell the difference between when there is something and nothing to be

done. When to save? When to let go?

I remember my brother when I was just a little girl in first grade having tea parties with stuffed animals. Jeff would kindly be another guest to help me playfully animate my inanimate friends, his six-foot frame folded awkwardly at my squat table, his long fingers challenged by the small, fragile cups. I remember the fear when the boys from my brother's high school interrupted our party. Dominick, the leader, saw the absence of our parents' car as an opportunity to bang the door, shout, and threaten Jeff. I don't understand the words, just the anger. What's this all about? "Homo." "Fag." A pained look on Jeff's face. Should we hide under the bed? No, Jeff says. We'll be okay. We keep on with our pretending, the tea party. I am confused. How could anyone want to hurt my brother?

I take a break from the crepe paper and crawl onto the empty side of the double bed with Jeff. Empty, except for his cats that now never leave his bony side. Mom calls it Fuzz Therapy. They cuddle him, Jeff pets them and is comforted. He's so skinny now his clothes, his sheets, seem empty. His brown eyes look out from shadowed hollows. His cheekbones and forehead are ever more prominent. The cats make room for me as I try to be near my brother. I don't know what to do but be there. I stroke his arm. I mindlessly murmur a song to him. I pray for his comfort. I don't think I'm as comforting as the cats.

The guests begin to arrive. A few at first, then in droves, until the ordinary three-bedroom, two-bath house is teeming with Jeff's admirers inside and out. The living room, family room, and kitchen are full, the back patio too, on this Phoenix winter night. People dressed comfortably but not comfortable, the event being what it is. Then things get going. A sea of tidy people. Heads bobbing above long-sleeved collared shirts, a few sweaters, one suit. Mainly men, a handful of women. Mostly strangers, some family. Our sister, Patty, can't be here—she's too sick to make the flight from North Carolina. She's sent a flower arrangement with Mylar balloons hovering above, shiny telegrams of "Best Wishes", "You're the Greatest", and a huge yellow smiley face. Aunt Audie reads Jeff the card. "I'm sorry I can't make it to your party. My heart and soul are with you always. I love you, Gracie. Forever yours, George." Their inside joke. Vaudeville's George Burns and Gracie Allen. Jeff smiles.



House Boat | Jeff Luse

Jeff's unique vision of a houseboat. From childhood on, he enjoyed anything "old"—music, boats, houses, cars, and people.

In the main living area, Jeff's friend Jim acts as a reporter, pointing a video camera, saying, "In case you don't get to see Jeff in person tonight, we're making this video for him. Anything you want to say?" One after another, people record memories and wishes for Jeff, my normally social, ebullient brother who is more recently reclusive out of necessity. "Jeff, you've really been good to all of us. You're great." "Jeff, we're rooting for you. We hope you are resting comfortably." I huddle in the kitchen, not really sure how to be social at first. A deli tray, a fruit platter; about as much company as I can handle just then. Still, I listen. They talk about the 1928 Packard and the baby-blue 1960 Lincoln in the garage. Jeff loved restoring old cars, doing most of the work himself, from the engine to the body to the upholstery. He'd ruined two family sewing machines before he and Dad figured out they needed something industrial strength. He enjoyed investigating and tracking down original parts to bring the grand old automobiles back to their full former glory. So many of these friends are from the classic car club in which Jeff was active. They talk cars, they talk Jeff. I watch. They chat and laugh; then a cloud blows over their faces, a memory of what tonight is about. Awkward, sad pauses.

Near the hallway other people begin to collect and wait to be

formally escorted back to the bedroom in groups of two or three, as if they are being permitted by security to meet the Queen of England. I'm happy to see it and yet angry inside, selfish—I want him to myself. Each small group speaks with Jeff briefly to tell him hello and good-bye, to tell him what is in their hearts, and to hear what is in his. I'm not proud of the selfish feelings. Richie's being quietly bossy. Directing people around; deciding time limits of the visits with Jeff. I want to go back. He says no. You had him to yourself all afternoon, he says, and many other days. Jeff needs to see his friends too. Richie's right, but I still hate him at that moment. I know he's trying to protect Jeff, and he's been helping Jeff, Mom, and me with so much. I remember him and me at the emergency room during one of the times earlier on that we thought Jeff was about to die. We decided—Richie and I—what we each could handle. He wasn't willing to pull the plug on Jeff, if it came to that. I didn't want to either. But I wasn't up to handling his tangled affairs after he passed. Does that make me a bad sister? Jeff wanted me to be ready to do both. I knew if I had to do the first, I could never do the second. Richie couldn't either. We sorted it out. As blood family, I took the life-and-death choice. As part of the family Jeff had chosen for himself, Richie agreed to handle his affairs. It never came to me having to pull the plug. But Richie's effectiveness tonight makes me feel ineffective, powerless in the face of the impending loss.

All these people—and overhearing the video postcards and side conversations—remind me of a fan club. My mind wanders to the concept of “celebrity” as it is safer there, me going all analytical about a word or a concept. It distracts me. I tell myself the famous and fabulous celebrities are just part of a make-believe world and, like real stars that are light-years away in the universe, they add no true warmth or meaning to our lives. Paper people in a rainstorm of attention, they melt. But tonight is not make-believe. And my brother's kindness touched many lives for real. He'd won two high-profile volunteer awards for his work with the elderly. Having been misunderstood many times in his own life, he triumphed by not letting it squelch his spirit. His sense of humor, generosity, and empathy survived and was healing for others. He knew what it was to be forgotten—or at least left alone—and was determined that these old folks would be neither. He'd seek out the most neglected,

nasty, or misunderstood and spend extra time with them. He didn't judge folks, he just listened. He didn't stifle, he encouraged. No wonder so many people were turning up on such short notice to pay their regards.

And so many others would have been here if they could've been—Jeff had fans amongst the old folks, as they appreciated how he eased their pain and helped them remember the good ol' days of their youth. Jeff was quite a hit when he'd park one of the classic cars he'd restored—maybe the pink Lincoln or the 1962 Studebaker—outside a window where he would lead them to see and stir up stories. They welcomed the polite young man who knew so many old songs—like “Tiptoe Through the Tulips”, “Has Anybody Seen My Gal?”, “It Had To Be You”—on the piano or would bring in an antique hand-cranked Victrola to play 78-size records. Their quivery voices would join in the song, they'd tap their toes or canes, and a light would shine from their cataract-cloudy eyes. He could play music from the 1880s through the 1940s like a pro, from memory or stacks of old sheet music. One song after another. Yes, they'd have come to the party too, if they could have, even if it would pain them to see that they were now healthier than their young helper.

There were already so many people here, too little time to keep taking the guests back to his bedside in pairs. And Jeff is tired. Deathly tired. He struggles to stay awake but keeps drifting off. His eyes glaze over, then shut. His mouth drops open. There must be a way for him to appreciate this beautiful assembly before it is too late.

Jeff himself provides the answer. Miraculously, in a determined act of willpower, Jeff decides to dress in a man's vintage dressing robe, matte black with subtle gold embroidery, reminiscent of the costume of a silent movie actor in his dressing room, something from an old black-and-white film. For tonight Jeff is a movie star. Any other day, before the illness struck, he was just like you and me, working normal jobs like the rest of us. But tonight he has an audience of some of the people touched by his care and compassion. They waited, wondering if they'd see Jeff again. They would. Richie and Dennis wheel him out to the press of people crowded in the house that, in the moment they see him, fall into an immediate, velvet silence. This appearance is unexpected by all. Surprised, we part to clear a path as attempts are made to help get Jeff's wheelchair—something we'd had for just a few days now—next to the



Ivy Mansion | Jeff Luse

Jeff's fondness for antiques extended to drawing old houses from his imagination. The originals, whether in ink, pencil, or oil paint, were much larger than this reduced reproduction.

antique baby grand piano. Everyone is holding their breath, watching attentively enough that five men, as if on cue, just step forward and lift the piano to make way for the chair to get behind it. They avoid knocking their heads on the Art Deco chandelier Jeff rescued from a condemned building; avoid disrupting the silver tray that rests on the piano, filled with crystal decanters Jeff collected from estate sales. Once in place, awkward with his oxygen tank and tubes, Jeff still manages to reach the keys and do, for the last time, what he so loved to do, for the length of his life, in the remains of each day.

He begins to play. Perhaps not as well as he once did, but all the more lovely for the effort. Perhaps not in perfect time as Jeff seems in the slightest bit of a hurry, as if listening to Charon's impatiently tapping finger as he waits to ferry Jeff across the river Styx. The mystic metronome rushes him as Jeff moves fluidly from one song to the next without pause. He plays little clips from many songs. Ragtime-era songs—like Joplin's "Maple Leaf Rag", "The Entertainer", and "Solace"—then brushes

quickly on classical music like Beethoven's "Für Elise". He loses his place and rasps "I lost that one" as he crescendos the keyboard and begins again. People chuckle. Jeff weaves in a few bars from his original compositions but, overall, old-time love songs prevail—the torch songs, the songs of hope and loss—"Stardust", "Fascination", "La Vie En Rose". Through the sad and happy tunes, he plays to a rapt audience. They take in Jeff's every move, his smile, his gleaming eyes, his frail face and form. Jeff's focused on the keyboard more than ever before, concentrating his waning will to do this. He doesn't see we are crying at the beauty and tragedy, that we marvel at the energy Jeff found for this final performance.

His eyes are bright but so sunken, his bones so apparent—the cancer may vanquish his body, but it cannot conquer his spirit. His life flashes before my eyes. I remember all I learned from my brother. I remember how confused I was the day he was shouted out of the house—banished, kicked out to fend for himself—he couldn't live with us anymore. I cried at his pained face, his pleading voice. I cried at the suddenness and chaos; at my inability to get a comprehensible answer for this atrocity. All I could get was that he was kicked out of the house and the family religion for being "a liar". What lie could be so bad to warrant this shocking overreaction?

My dad and then stepmother were so uncomfortable with the truth, they couldn't tell me. Finally, later, they said that the lie was about his sexual orientation. Homosexuality is a sin in the religion of my youth—Jehovah's Witnesses, not that it matters as several religions feel similarly—but it took them days to be able to say the words that their son was gay. I feel ashamed that, in my youthful ignorance, I then parroted their rejecting words—for the stain of the intolerance bred in from birth is hard to wash out—and I didn't want a reprise of what he had suffered. Had I spoken in his defense, I could be in trouble too.

But that's what made my brother's choice to embrace his true self so much more courageous—he was raised with that intolerant belief system and still felt compelled to let his heart love. To me, he wasn't kicked out for lying. He was kicked out because he stopped lying. Shortly after his departure I began to question many things, quietly, deep in my heart. *What is love? If God is love, isn't any love good? Which*

*is more important, sex or love? Would a loving God endorse families being ripped apart over love? Can't we at least frost condemnation with civility?* I tried to reconcile a variety of family and religious paradoxes, inconsistencies, and hypocrisies—and my own intolerance melted away. I “forgave” my brother—though that’s not the right word, for there was nothing to forgive. Better put, I “accepted” my brother, but my immature realizations and unseen acts of grace were mine alone and could not bring him back into the prickly family situation. I comforted myself with half-truths, like he was better off being out there on his own, making friends who’d love him for who he really was, being with people he didn’t have to lie to or lie for.

I missed my brother and wanted him back in my life. But that was not permitted, except in the briefest of snippets. He tried to go “straight” for a while, it seemed, as one day he showed up at the door with a friendly woman and announced he was engaged. I can’t remember her name, but the folks invited them in—after all, maybe Jeff had learned his lesson, and we wanted to be nice to this potential convert. Then that was that. Never heard about her again. Had he really been engaged? Or had a friend posed as his fiancée, a beard to disguise his true self, so he could see his family for a visit? Just snippets of visits, rumors of news. Very little time together for too many—and yet too few—years.

Snippets and rumors until years later, when I was kicked out of the family and the religion myself. It was a silver lining that he was on the other side, waiting for me. Reuniting with the family he missed so much was important to him. Not just our immediate family, but the extended family that had been scattered to the wind by this or that controversy or misunderstanding. And that’s one of the reasons this party is also so important to him. We’d talked about it. He threw a graduation party/family reunion for my final degree just two years before, and family who’d not seen him for years deigned to come to his house for whomever they hoped to see there. That was the first step—get family to at least come over for *some* reason and, in so doing, acknowledge he still exists. Then, here he is, dying at 42, and he had one more chance to integrate the sides of his life, at whatever surface level it may be.

By now so many years had passed since his original “sin” that some

people who'd rejected him had had their own sort of comeuppance, and some others had tempered with time. This time, with such short notice, there were relatively few family compared to my graduation party, but, thankfully, some of those who'd mellowed their intolerance, to one degree or another, were now here in Jeff's house, listening to him play his swan song, standing elbow-to-elbow with Jeff's homosexual friends. My mom is here, as she has been for four out of the six months of Jeff's decline since his diagnosis. She'd flown out from North Carolina to live with him and take care of him, with relatively little help from others. A good mom making up for lost time that divorce, and then the religious rules, had taken from them. Nothing stops her now; she's been here for him.

I remember the last time I saw Jeff before his diagnosis. It happened to be Mother's Day. I asked him to help me hang a curtain rod. He looked as strong and healthy as ever, I thought. But he got winded awfully easily. He'd lose his breath pretty quickly just going up and down a dinky stepladder a couple times and holding his arms above his head briefly. He needed to pause to right himself. Without offering details he mentioned he hadn't been feeling his best, but his M.D. kept dismissing his symptoms, saying he was too young to worry. Our task complete, we went to dinner. Middle Eastern food? That'd be fun to try. As we shared hummus and gyros, we jabbered about writing, art, food. I also reminded him that one can get a degree without getting "A" grades in the classes, that maybe his doctor, while well-intentioned, wasn't at the top of the heap in the brain department. Maybe he needed to get a second opinion. Six weeks later we knew. He had inoperable masses of cancer in his lungs and colon.

Stepmother Marcia and Dad are here. Amazing. Dad's really had next to nothing to do with Jeff for years, even in these last months. But he's here tonight. At last. Literally. That uncomfortable look on Dad's face could be that he's not sure he should be here amongst "those people", or it could be that it is finally sinking in that his only son is not long for this world. Maybe both. I remember when Jeff got sick. Dad said it was probably his "lifestyle". *Had he forgotten that Patty was so sick too? That his kids either inherited bad genes or were, more likely, the unintended "environmental" victims of being conceived and raised*

*on a toxic Superfund site? Had he forgotten that one of Jeff's early jobs was around chemical fumes all day, in the days before workplace safety standards were common?* “No, Daddy,” I said. “Jeff doesn’t have AIDS. He’s not even HIV positive. He’s got Stage 4 cancer in the lungs and colon. Well, it’s everywhere now. It’s metastasized to his liver, kidney, and spleen. His brain. You won’t catch anything. Please come visit him.” Jeff tried everything, including chemo, intravenous laetrile, and juice fasting. The cancer was discovered too late for anything but a miracle to work. Dad and Marcia drove over to Jeff’s a couple times. Dad would wait in the car while Marcia brought something to the door—a vegetable juicer machine or whatever they thought might help. I’d go out to the car. Dad would say he had a cold or some bug that he didn’t want Jeff to catch in his weakened state. Maybe he did. Whatever the case, Dad was here now; that counts for something. I know that Jeff considers this party a success, as much as it could be given the circumstances. He finally felt accepted.

Jeff plays his piano medley until he is spent—which, these days, does not take long. He stops. Mom kisses his forehead. Jeff smiles. “Thank you all for coming here. I love you all. Let the visiting commence!”

Then the applause begins—much applause. Followed again by silence as he is wheeled, beaming, from the room. But this time the quiet is punctuated with Jeff asking Uncle Jessie, also in a wheelchair, if he wants to race. Punctuated with accolades like “I love you, Jeff” or “That was beautiful, Jeff” as people on either side of his path reach out to Jeff like fans seeking the rare opportunity to touch a celebrity passing them by on the red carpet.

I watch. My mind escapes back to its analytical safety net, and I know that, for me, a “celebrity” isn’t a distant luminary, but one who shines in my own world and is as real as the big brother, the best friend, the firstborn son, or the favorite cousin, as Jeff was. Not a cultural icon, but someone who impacts my soul, who shows me how to love and how to be happy with who I am and with others for who they are. Not an idol glowing in the limelight, but the person who stands next to me in daylight. Or night light. There each day, or at least when you need them most.

Jeff is settled in his room once again; only the immediate family



Rabbit's House | Jeff Lusé

Jeff titled this “Nelly’s Hollow”—a mansion for a rabbit, though he was particularly fond of cats. His active and detailed imagination showed in all aspects of his life.

and closest friends are with him in the dim light. The sounds of the party muffled in the distant parts of the house, we take turns moving closer to the bed, each having a private word of love and appreciation. I hear tidbits. “You’ll always remain in our hearts.” “I know you have to go.” Jeff is so tired now. So tired. Every remaining ounce of his precious little energy spent on the Herculean effort to provide his last gift to us, to bring people together in the spirit of music. Leaving Jeff to sleep with his purring cats cuddled next to him, his last wish was granted—he’d had a “Bon Voyage” going-away party instead of a funeral. He died in his sleep before the very last of his guests had left.

Jeff did far more for me than I ever did—ever could have done—for him. Even though I had challenges as his medical power of attorney—sodden with the emotions and dramatic circumstances his demise involved—it was my privilege to be able to see him more and assist my mother in his care the days between his diagnosis and death. His pain and shared grief made those six months crawl by in

some ways. Happier things—like his goofy jokes, sly sense of humor, or watching a funny movie to distract him from the pain—made the time pass at the speed of light. The pain. I remember coming over for a couple days at a time to give Mom a break. I'd try to sleep in the guest room, but I couldn't. I could see him through our open doors, sitting up, tapping his hand, then his foot, then his hand. So stubborn. Not wanting too many drugs to help with the pain. He wanted to be lucid, in control—best he could be.

So I'd get up and sit with him; our conversation an added diversion to accompany the constant tapping. We'd talk about whatever, sometimes light, sometime serious. He didn't want to start hospice, he said. Then he'd really have to admit he was dying. He knew this through his work with the elderly. He wasn't ready yet. There was so much to do. I didn't want to extinguish his hope, but Mom and I needed help; Jeff needed help. I told him our calling hospice wouldn't mean he *had* to die. If he were to recover, then hospice would celebrate along with us. If he didn't need hospice at some point we would just cancel it. I teased him that hospice would happily forgive him for living. But would he, please, consider it for Mom and me, and for Lois, Brooks, Jim, Harry, Mark, Ritchie, Dennis, and the other friends we'd sometimes call for help? Jeff only let us call hospice less than a week before he died.

That's okay. I respected Jeff's choices. Especially this late in the game, it needed to be more about him than Mom or me. While the few days of hospice support did help us manage at the very end, it was the months of grief counseling that really helped. And if he'd had the morphine sooner, I'd have missed some of our scant opportunities to visit. I am grateful to have sat up with him when the pain wouldn't let him sleep, to have made banana pudding with vanilla wafers for him—and whatever else he might crave—even though he rarely had the strength or the stomach to eat it. I'd stir the pudding on the stove, round and round with a wooden spoon. Losing myself. I'd arrange the wafers just so in short old-fashioned clear glasses so he could see the designs I tried to make with the cookies. Losing my brother. I'd slice fresh bananas to use as garnish, just like the picture on the box. These little efforts and the sweet aroma of the food still mattered.



Jeffery Lusé | Courtesy of Stephanie deLusé

Jeff in his late 30's, pictured with one of his beloved antique cars. (Jeff did not use the "de" in his legal last name but did often use it in his art work.)

*In memory*

*Jeffery Vincent Lusé*

*March 27, 1958 – January 5, 2001*

*"I will make melody to my God as long as I am." ~ Psalms 146:2*

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Stephanie is an Honors Faculty Fellow and Principal Lecturer in Barrett, the Honors College at Arizona State University. Her teaching has earned her honors including the ASU "Last Lecture" (2009), Featured Faculty Award (2006), and the Outstanding Faculty Award (2005). Her writing appears in literary journals including *Emrys* and *The MacGuffin*, in popular press books (e.g., *The Psychology of Survivor*, *The Psychology of Joss Whedon*, and *The Psychology of Superheroes*) and academic journals including *Family and Conciliation Courts Review* and *Family Processes*.