Stories to Live and Die By: In Memorium

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By Frankie Condon

*What I am offering here is not a theory but rather a story about the decent society...It is not a medieval-style allegory in which Honor and Humiliation are personified heroes, but a story in which...the picture obtained is that of a utopia through which to criticize reality.*

~Avishai Margalit

In hindsight, I should have known Suzy was dying nine months before her life actually ended: the night she saw “the sign of the rested day” on her bedroom wall. But I had never witnessed the passage from life to death before and had no means of recognizing where my mom was headed. Neither of us had a map for that particular journey. It was a school night and the time of evening when teenagers remember that they haven’t done their homework, which, of course, requires your assistance; fight over time in the bathroom; require one last snack; and don’t answer questions because they’re busy taking selfies for Instagram. The time of night when the exhaustion of the day transforms from a tickle at the back of the mind to bone weariness. “Frankie! Fraaaaankie,” Suzy called from her room. I had already helped her into her nightdress, washed her face, brushed her teeth, and had transferred her from her chair to the bed. I had turned the television off at her request and gone off to convince the kids that it really was time to head upstairs. All that remained of our bedtime ritual was for me to turn off her light.

“What do you need, mom?”
“Do you see that?”
“Do I see what?

Suzy on her honeymoon circa 1954
I was only half attending. My other half was listening to the sounds of an argument breaking out between the kids, who were gathered around the dining room table.

“THAT! Do you see it?”
“Mom, I’m sorry. I don’t know what you’re talking about.”
“That! There. Right there!”
“Where?”
“There! It’s the sign of the rested day!”
“It’s the what?”
“The sign of the rested day. Right there! Look, Goddamn it!”

Grace, who is twelve, comes into the room.
“What’s the matter?”
“Gramma is seeing something on the wall.”
“IT’S THE SIGN OF THE RESTED DAY!”
“She sees the sign of the rested day on the wall.”
“The what?”
“Oh God,” says Suzy.

My husband, Mike, comes into the room.
“What’s the matter?”
“Oh God,” I say.
“Mike, you can see it,” says Suzy hopefully. “Look, it’s there: the sign of the rested day. See?”
“The what?”

By now, Lucy, who is fourteen, and Dan, sixteen, have come in as well. We are all searching for the sign. At Mike’s suggestion I began to make my way around the room, pointing to things and describing them.
“Look, mom. This is a wall. This is the door that leads to your bathroom and this is your closet door. This is your dresser...”
“Don’t tell me I’m crazy!”
“Suzy,” says Mike, “nobody thinks you’re crazy.”
“Please,” says Suzy who by now is in tears. “Say you see it too.”
“I think I see it,” says Grace.
“Shut up!” says Lucy.
“Maybe it means you’re supposed to go to sleep,” says Dan. He leaves and Lucy follows.
“Don’t leave me,” Suzy wails at me.
“I’ve got the kids,” Mike says, and leaves to herd teenagers to bed and taking Grace with him.
“Mom, I’m so tired. I have to go to bed.”
“You hate me. Why are you so mean?”
“Mom, I love you. And I’m exhausted. I have to sleep.” Five years of waking at three AM to write, revise, and finish a book before taking on the rest of the day—kids who train in their sports before school, classes and committee meetings, feedback on student papers and grading, more childcare, cooking, and cleaning; and fifteen years of caregiving—have taken their toll. I am always tired. My hair has gone from brown to gray.

“The sign, the sign,” Suzy moans.

“I can’t stay! I can’t take care of you or anyone else if I don’t sleep.”

“Please, Frankie, please!”

“I. Have. To. Sleep.” I am shouting.

Suzy turns her face away from me. “You’re so mean,” she says.

There is nothing else to say. She is right. I am mean. And tired. And I can’t. I Just. Can’t. Stay.

I turn out her light and go to bed.

Many years ago, before I met my husband or gave birth to my children, my mom and I traveled to Barcelona, Spain together on a holiday. Suzy had been diagnosed with chronic/progressive multiple sclerosis twenty years before our trip. She could still walk a short way (a few steps from wheelchair to bed, chair, or toilet), but mostly relied on a push-wheelchair. We stayed in a gracious hotel just off Las Ramblas during the week preceding and through the Easter weekend. I remember feeling young and strong and determined during that trip. Barcelona was not, at the time, a terrifically accessible city, but Suzy and I were clear that we would see as much as we could see together. I muscled her chair along winding streets, over curbs, up and down stone stairways. We watched mimes and listened to musicians, drank wine together at street cafes, ate our dinner so late at night that the achievement of sleep was a worthy struggle. Together, we fell in love with the architecture of Antoni Gaudi: with the sea- and landscape shapes and colors of that terrible and lovely imagination with which he endowed residences, gardens, and, of course, his masterwork: the extraordinary cathedral, Sagrada Familia.
The Sacred Family. The cathedral, it seemed to us, appeared as if a mountain had melted away and left its heart, revealed, both to grace humanity with hope and to tremble our certitudes. Or, we said, if to see the shifting qualities of light across the face of the Grand Canyon was to view the mind of God as nature might reveal it, to see the Sagrada Familia was to view the mind of God as the human imagination at its apex might conceive it. The Sagrada Familia, we thought, represented in architecture the infinite terror and generosity, the holiness of living among and for one another: living not merely of necessity, but with intentionality within the family that is all-our-relations—the human family.

Within five years or so of our Spanish journey, Suzy could no longer walk. Nor could she dress herself, transfer herself from bed to chair, bathe or relieve herself. By then I was married to my partner, Mike, had given birth to a son, and was expecting a second child. The details of the arrangements by which Suzy came to live with us have been obscured by time. I remember a telephone conversation with her best friend and housemate. Loyal and infinitely generous, Brian had lived with and cared for Suzy for more than a decade. But Suzy’s need for everyday forms of assistance had exceeded the comfort either of them felt with the arrangement. Suzy, I think, understood the obligation to care for her sacred family even as we cared for her. She felt that she had asked enough of Brian; it was time for someone else to step in and Suzy had chosen me. Suzy could no longer care for herself. Brian could no longer be responsible for her care. I would be responsible now, with Mike to help me. Although I didn’t understand this at the time, we were all we had. There would be no meaningful, no lasting, no significant aid from any agency
or institution until my mom entered hospice care fifteen years later. Mike and I searched for a house in which we might all live together, and talked together about how we would make our lives as an extended family.

Suzy arrived in the spring of 1998 when our daughter, Lucy, was about six weeks old. The rooms Mike and I were renovating to make accessible for her were not yet finished so we set up her bed and lift in our living room. In the mornings, I would nurse Lucy while Mike prepared breakfast for our two-year-old son Dan, then hold the baby while I bathed and dressed mom and helped her into her chair. I remember that spring as one in which the sun shone perpetually. I remember the smell of cut grass; Mike building a garden and composting bed, and Suzy watching as Dan and I planted vegetables. I remember sobbing with exhaustion and overwhelmment, sucked dry by nursing in every sense, and wondering what we had done and how we would ever manage to care for one another. For it had quickly become apparent that my roles had multiplied and morphed in ways I had neither understood nor predicted.

When Suzy came to live with us, I became something more than professor and writer, wife and mother, daughter and caregiver. I became also an artificial person, if not in the legal sense then in a social one: I became a functionary within a web of systems, institutions designed to mete out care management, but not care, itself. I became a mediator between those systems and institutions and my mom. I had been designated to provide everyday living and medical care to one who could no longer care for herself in terms intelligible to those systems and institutions; to provide care those systems and institutions would never provide, but upon which Suzy’s life depended. And this designation was sustained, legitimated, and also made invisible by a dominant social narrative of the caregiving daughter as dutiful and self-sacrificing, stoic and heroic; a narrative so prevalent, so absorbing that the sound and sense of any counter-stories my mother or I—or both of us—might tell were deadened, silenced absolutely before any sense could be made of them.

There had been a period of time in my life when I taught writing in a maximum-security penitentiary in upstate New York. During that time, when friends and relatives learned where I was teaching, they would frequently say things like, “you’re so courageous to teach in such a place.” So profound was their conviction that to teach writing in a prison was both foolhardy and saintly that nothing I said about the reality of that work could be heard or understood—the ways in which my students and I laughed together; the degrees to which my students pierced my assumptions about them and about myself with what seemed in my experience nearly unmatched intellectual
ferocity; the extent to which we seemed to like one another even in our strangeness to one another; the things they taught me—oh, the things they taught me! I was trapped in the story of the heroic teacher and anything I said to counter that narrative became merely more evidence of my courage. I imagined the experience as akin to trying to prove you’re sane from within the confines of an asylum—where everything you do and say and the more sane you try to appear, the more insane you are perceived to be.

When Suzy came to live with us, I was once more caught up in and bound to the filaments of the web of master narrative, this time about mothers and daughters, about caregiving, and about courage and heroism. If I talked about the joy, the honor, the fulfillment of life with my mom, I became “uncomplaining.” If I talked about how hard the work was, how sad I felt at times, how isolated our family now was from the lives of those without such responsibilities, I became “strong.” Now these may seem like first-world problems—analogous to the frustrated whine of a poor little rich girl. I was not, after all, my mother, whose illness was daily robbing her of her ability to do for herself. But—this master narrative served and continues to serve a powerful enabling function for the creation of nearly uninhabitable conditions for the chronically ill and disabled as well as for their families. There are particularities unique to the stories of the chronically ill and disabled as well as those that are unique to the stories of their caregivers; but these narratives are braided together—interdependent and mutually contingent. The master narrative that effaces or renders insignificant the relationship between stories also sustains a culture in which the humiliation, degradation, and marginalization of the ill and disabled are both systematized and made invisible. The stories of the ill and disabled are bound up with those of their daughters and sons, partners and friends who provide what society will not—unless the individual can pay the medical industrial complex for the care that is needed merely to live. Our story, in spite of what may be said or written about us or what laws or policies might be established to surveil and discipline us is that we are part of one another, bound to one another, and the reciprocity of our relations is not realized merely in the profanity of

...Beyond cheerfulness and patience, people don’t generally expect much of a cripple’s character. And certainly they presume that care, which I have placed at the heart of moral experience, flows in one direction, “downward”: as from adult to child, so from well to ill, from whole to maimed.

~Nancy Mair
exchange value, but in the sacredness of our belonging with, to, and for one another.

Michael Berube, in his book, *Life as We Know It*, writes that his purpose as a caregiver and as a writer representing his son, Jamie, who was born with Down Syndrome, is “to ask questions about our obligations to each other, individually and socially, and about our capacity to imagine other people.” “I know how crucial it is,” he writes “that we collectively cultivate our capacities to imagine our obligations to each other.” (as qtd. in Frank 62) Berube notes that he, as one who represents a child with a disability, has the task of narrating his son to his readers “with all the fidelity that mere language can afford, the better to enable you to imagine him—and to imagine what he might think of your ability to imagine him.” (as qtd. in Frank 63)

In her book, *A Problem from Hell*, Samantha Powers suggest that the language of public policy is, by design, so abstracted from the material conditions of the lives of the governed that it cannot, in fact, account for or meaningfully address those conditions. Such language cloaks the political valences and economic bottom-lines to which a government is committed in discourses that advance the appearance of objectivism, rationality, and “fair-mindedness.” As public policy is actualized in the practices of institutions, its discursive logics are revealed and found wanting. Within this context, to ask for help from an institution suggests that neither the patient nor the caregiver is self-reliant: an admission that positions patient, caregiver, and the coerced-into-existence dyad of we-two in a deficient relation not only to the institution, but to American values writ large.

The request for help, in other words, places those who make the request under the sign of moral failure. If the chronically ill and disabled and their caregivers are not, in fact, courageous and heroic in their stoicism, the quality of their integrity must be examined and the means of this examination is the work of a network of medical and government bureaucracies. The challenge is to prove to a bureaucracy—a faceless other with whom one may only communicate through the filing of forms in which what one can say and how one may say it are severely constrained—to prove to a bureaucracy that you and your mom are not, in fact, impostors or spongers, liars or thieves. Navigating one’s way among the functionaries who gatekeep on behalf of the bureaucracies that conserve medical and social aid requires the acquisition of an array of institutional literacies never taught in school, as well as a rather exceptional literate adaptability—for the forms change arbitrarily as do the kinds of proof of need required to demonstrate the truth of information submitted on those forms. The time required to fill out forms, gather proofs, gather more proofs, fill out more forms, stay on
hold on the telephone waiting for answers, call different numbers to get different answers, get referred back to the original number in endless loops is soul destroying. And unpaid family leave to do that work is no leave at all. Rarely do the bureaucracy or its functionaries acknowledge nor do they seem to recognize that even as they search for evidence of our mendacity (like Sauron scouring Middle Earth for signs of Frodo), we are evaluating them. And finding their imaginations impoverished, warped, and wicked. It is easier to accept the narrative of self-reliance, easier not to ask for help. Suzy and Mike and I came to understand death panels. And they were not proposed in “Obama Care,” but are actualized in a medical industrial complex operating with impunity under late capitalism.

Multiple sclerosis sucks, but it is the bureaucracy of the medical industrial complex that destroys hope.

On any given day, you could tell how Suzy was feeling by how soft or hard her edges were. On bad days, she could be quiet or sad, confused or more sad. On good days, she could be a terrific conversationalist with a biting wit and brilliant analysis of history, politics, and literature. And, the truth is, the more biting her wit (really, the meaner she was), the better she was feeling. One night, after a particularly long and trying day at work and having made supper for the family while assisting with homework, mediating sibling conflicts, and answering several pressing emails left over from the day, we all gathered around the table to eat. Mike set Suzy’s tray in place on her wheelchair while I filled her plate. I cut up her chicken and vegetables into bite sized pieces and helped her arrange her fork in her hand so she could feed herself. I sat down to eat. Suzy took a bite of chicken, chewed for a long time, and then sighed loudly. “Oh God.”

“What’s the matter, Mom?” I ask (sighing inwardly myself and thinking “uh oh, it’s a sad day.”)

“This chicken is fucking awful.”

The kids smirk. Mike looks away to hide his smile. It’s true. The chicken is fucking awful.

But suddenly I’m enraged. I’m listing in my head all the tasks that fall to me over the course of a day, the daily impossibility of doing everything that needs to be done, and the quotidian certainty that in trying I will fail at nearly everything I attempt.

“What’s wrong with it?”

“It’s disgusting! It’s dry; it’s overcooked; I can’t eat this.” Suzy waves a forkful of chicken at me. The kids duck their heads, grinning.
“You know, Mom,” I say, “when you were teaching full time and raising three kids, no one ever talked to you like that about your cooking. Everyone knew how hard you were working and we all cut you some slack.”

“I never made anything as terrible as this goddamned chicken,” she said.

At the moment it happens I am sickened, the way, as a kid, my stomach used to leap in the car when my dad accelerated over a rise in the road. Everything is out of control. Chronic illness and disability have taken Suzy and me into a turbulent flow that drowns sense and meaning. The past seemed to promise something other than what it has, in fact, delivered. The present is not what we imagined it would be; the future is unimaginable (Frank, Storyteller 55). Still, days later that dinner becomes a funny story that I tell my sister. We laugh over the phone together. I laugh until tears flow. Suzy could be so mean. And so right. And multiple sclerosis sucks.

Suzy was a professor of history. She was smart—so smart that thirty years after the completion of her dissertation on Thomas Jefferson and the Louisiana Purchase, her graduate school advisor, then in his nineties and still writing and editing, continued to assert that her work was the definitive account of that historical moment in the field. As she began teaching, however, in the 1960’s, her interests turned to African American history and to the representation of Black experience in popular culture. She pioneered the first courses in Black history at her university. Suzy was deeply committed to racial justice. She made mistakes; there were moments when she failed to enact the principles to which she had dedicated herself. I know of no one who could righteously claim not to have erred. But Suzy never waivered in her progressive vision of a fully realized multiracial democracy and aimed her teaching, her writing, and her parenting always toward that possibility.

On November 4, 2008, Mike and I stopped work early in order to take Suzy to our polling station to vote. I voted first and then helped Suzy complete her ballot. “Who do you want to vote for for President?” I asked her, somewhat ungrammatically. “Really?” she said. “That’s not a question you need to ask.” And taking the pencil in her hand, with my hand to guide its tip, she marked her vote for Barack Obama. I inserted her ballot into the voting machine and we
smiled at each other. I put her “I voted” sticker on her shirt and took one for myself as well.” Mike took our picture just outside the polling station before we headed for home. That evening, after we had all eaten supper, the whole family gathered in Suzy’s room to watch the election results come in. As the first reports calling the election for Barack Obama were announced, I began to cry. I looked over at Suzy and tears were rolling down her cheeks too. Suzy didn’t live to see that fully realized multiracial democracy, but whatever else might come, we two had seen that day. Together.

Death came gently for Suzy in the end. The care that had been denied to her when living was her objective, was lavished on her as she lay dying. I don’t mean to sound bitter. The hospice nurses and counselors were extraordinarily kind. But the tragic irony of the situation does strike me now and then. Two nights before Suzy passed, she woke briefly though she was hardly able to speak. I called to Mike and the kids who came to join me at her bedside. Dan and Lucy and Grace took turns holding her hands. We all told Suzy how much we loved her and together we said the Lord’s Prayer. Suzy tried to speak. We leaned in to listen. Her eyes focused, but just barely, on the children. “So beautiful,” she whispered. “You are so beautiful.” She slept then and did not wake again. What would it mean, I wonder now as I mourn the loss of my mother and am pressed to learn who I am now that I am not what I was to her—what would it mean to build a society in which the story of our moral obligation to care well and deeply for one another as a sacred family would explain and legitimate the practices of systems and institutions designed to enact that obligation—to make collective care real and actionable in the everyday sense? Would the enactment of this moral imagination be any worse, materially speaking, than the enactment of the economic calculus of the exchange value of human lives that shapes the current state of our relations? I think the world would be immeasurably better. In such a world, there would be a story that opens the social mind to the humanity of mutual-caregivers both abled and disabled, well and ill. There would be a story that, having deconstructed the twisted, over-determined master narrative of self-reliance, courage, stoicism, and heroism, would “retain a vision of the human face[s]” of actors, now released from the isolation of the dyad into a vast web of deep relations made possible and conditioned by a collective recognition of the social obligation we all bear to care for one another. (Frank, “Generosity” 66) And that’s a story that would go a long way toward the creation of a “habitable world” for those in filial relations shaped not wholly, but in part by chronic illness and disability.

Last summer, my daughters began to beg me to read John Green’s novel, “The Fault in Our Stars.” I resisted. I didn’t say I wouldn’t read the
book. I simply continued to lay it aside and, when pressed, to affirm that yes, I would read it soon. Finally, about a month ago, I gave in. I finished the book over the course of a quiet afternoon when no one else was home. I am glad I waited. To have read the book in the earliest throes of mourning might have done me in. Even a month ago, it was nearly too much.

“You do not immortalize the lost by writing about them,” says Green. “Language buries, but does not resurrect.” I admit I sobbed as I read those words. It may be so—that language cannot recover for us those whom we have lost. But that really isn’t the job of language is it? Language’s labor has never been to bring back the dead, but rather to create new worlds—work that language can only accomplish because we have known, lived with, and cared for those who came before.
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